NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE GUIDELINE NG86

People's experience in adult social care services: improving the experience of care and support for people using adult social care services

February 2018

Update information

September 2020: We linked to the NICE guideline on supporting adult carers in the recommendation on offering a carer’s assessment. We have incorporated footnotes into the recommendations in line with accessibility requirements.

These changes can be seen in the NICE guideline at www.nice.org.uk/guidance/ng86.

Contents

Introduction

The Department of Health in England has asked the National Institute for Health and Care Excellence (NICE) to develop this guideline on improving the experience of people who use adult social care services.

In 2015-16 there were over 800,000 people receiving long-term care and support (more than 12 months) from adult social care. During this time services also responded to a further 1.8 million new requests for care and support (including short-term support) (Community Care Statistics: Social Services Activity, England – 2015 to 2016 NHS Digital). The core purpose of adult care and support is to help people to achieve the outcomes that matter to them in their life. People's experiences of care and support, and the extent to which they feel supported to live their life as they want to, are therefore of key importance.

In 2016, 64% of respondents to the annual personal social services adult social care survey said they were either extremely or very satisfied with the care and support they received. However, only 33% said that they had as much control as they wanted over their daily life, 18% said they had some, but not enough, control and 6% had no control at all.

This guideline is developed in a context of working towards better integration of health and social care. For people who use services, integrated care means being at the centre of their own care, and not having to re-state personal details, symptoms or needs several times, or falling between gaps in disparate services. Relevant to this is the Care Act 2014 that places a duty on local authorities to integrate health and social care and related services where this promotes wellbeing, and prevent, reduce or delay needs.

This guideline covers good practice in the care and support of adults, including people with learning disabilities, physical disabilities, sensory impairment, and mental health or physical conditions. It aims to improve peoples' experiences of social care services. It is based on evidence about the views of people who use services on what is important to them in their care and support.

What does this guideline cover?

The guideline covers care and support for adults, including people with learning disabilities, physical disabilities, sensory impairment, and mental health or physical conditions. The guideline applies to all settings where care is delivered, including people's own homes, and residential care and community settings. It also takes into account a range of inequalities that people may face, as identified in the equality impact assessment.

This guideline does not include health services, including clinical mental health services. It also does not cover services and support specifically aimed at carers. (This will be addressed in a separate NICE guideline on carers, which is currently in development.)

Who is this guideline for?

This guideline is for:

- Practitioners working in adult social care services in all settings
- Service managers and providers (statutory and non-statutory) of adult social care services
- People using services, including those who fund their own care and support, and their families, carers, advocates and the public
- Commissioners of adult social care services.

It is also relevant for:

- Professionals working in and providing housing support.
- Community and voluntary organisations representing people who use services and their families.
- Local authorities.
- Health and wellbeing boards
- Local Healthwatch groups.

How has it been developed?

The voice of people who use services has been central to the development of the guideline. It has been developed by a Guideline Committee of people who use services, and carers and professionals using information from an extensive review of research evidence, and from expert witnesses. The development followed the methods outlined in Developing NICE guidelines: the manual.

Equality and diversity issues have been considered throughout the development of the guideline. Often, best practice identified in relation to the research evidence for particular groups was considered to represent good practice for all groups, so has contributed to recommendations for all adult social care service users.

What is the status of this guidance?

The application of the recommendations in this guideline is not mandatory. Different types of NICE guidance have a different status within the NHS, public health and social care. Although there is no legal obligation to implement our health and social care guidance, health and social care practitioners are actively encouraged to follow our recommendations to help them deliver the highest quality care. Our recommendations are not intended to replace the professional expertise and judgement of practitioners, as they discuss care and support options with people.

How does it relate to legal duties and other guidance?

This guideline does not replace statutory duties and good practice as set out in relevant legislation and guidance, including:

- Care Act 2014 and associated guidance
- Equality Act 2010
- Mental Capacity Act 2005
- Accessible Information Standard
- UN Convention on the Rights of Persons with Disabilities
- Human Rights Act 1998.

This guideline aims to complement legislation and guidance by providing evidence-based recommendations about how to improve people's experiences of care. Actions already required by law, or recommended in guidance, are not replicated here unless there was evidence to suggest that these were not happening in practice, or were of particular importance to people's experiences of care.

1 Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Overarching principles

1.1.1 Recognise that each person who uses services is an individual. Use each person's self-defined strengths, preferences, aspirations and needs as the basis on which to provide care and support to live an independent life[1].

1.1.2 Support people to maintain their independence. This means finding out what people want from their life, and providing the support and assistance they need to do this[2].

Co-production and enabling people to make decisions

1.1.3 Respect people's right to make their own decisions, and do not make assumptions about people's capacity to be in control of their own care and support (for example, if the person is severely disabled).

1.1.4 Actively involve the person in all decisions that affect them.

1.1.5 Provide support to people, if they need it, to express their views, preferences and aspirations in relation to their care and support. Identify and record how the person wishes to communicate and if they have any communication needs (in line with the Accessible Information Standard). This could include:

- advocacy support

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[1] This recommendation is adapted from the NICE guideline on patient experience in adult NHS services.

[2] This recommendation is adapted from the NICE guideline on patient experience in adult NHS services.

- an independent interpreter (that is, someone who does not have a relationship with the person or the services they are using) to enable people to communicate in a language they can readily converse in, including sign language
- a carer, if that is what the person wants
- communication aids (such as pictures, videos, symbols, large print, Braille, hearing loops)
- evidence-based techniques for communication
- additional time to understand and process information
- environmental conditions that support communication, such as clear lighting, and minimal noise interference.

1.1.6 If a person lacks the capacity to make a decision, the provisions of the Mental Capacity Act 2005 must be followed.

1.1.7 Use plain language and personalise the communication approach to encourage and enable people to be actively involved in their care and support. If technical language or jargon has to be used, or complicated ideas are being discussed, take time to check that the person, or a carer who knows them well, understands what is being said.

1.1.8 If a third party or advocate is supporting someone to give their views, ensure that enough time has been allowed for them to do it.

1.1.9 Local authorities and service providers should work with people who use adult social care services and their carers as far as possible to co-produce:

- the information they provide
- organisational policies and procedures
- staff training.

Access to care

1.1.10 Ensure that everyone with social care needs has access to services based on their needs, taking account of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation, and socio-economic status or other aspects of their identity.[3]

1.1.11 Service providers should be aware of the cultural and religious needs of people who use services, and provide care and support that meets these needs. Examples include treatment choices, food choice and preparation, enabling people to dress in accordance with their culture or religion, personal grooming, or changes in timing of services around religious festivals – for example, during Ramadan.

1.1.12 Commissioners and service providers should consider seeking advice from voluntary and community sector organisations such as disabled people's organisations and user-led organisations with expertise in equality and diversity issues to ensure that they can deliver services that meet the needs and preferences arising from:

- gender, including transgender
- sexual orientation and sexuality
- disability
- ethnicity
- religious and cultural practices.

1.1.13 Ensure that people who use services and have caring responsibilities (for another adult or a child) receive support to access social care services, including information about childcare, or respite care[4].

Involving carers, families and friends

1.1.14 Ask the person at the first point of contact whether and how they would like their carers, family, friends and advocates or other people of their choosing (for example, personal assistants) to be involved in discussions

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[3] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

[4] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

and decisions about their care and support, and follow their wishes. Review this regularly (at least every 6 to 12 months), or when requested[5].

1.1.15 If the person would like their carers, family, friends and advocates involved[6]:

- explain the principles of confidentiality, and how these are applied in the best interests of the person
- discuss with the person and their carers, family, friends and advocates what this would mean for them
- share information with carers, family, friends and advocates as agreed.

1.1.16 If a person lacks the capacity to make a decision about whether they wish their carers, family friends and advocates to be involved, the provisions of the Mental Capacity Act 2005 must be followed.

1.2 Information

1.2.1 In line with the Care Act 2014, local authorities must provide information about care and support services for people and their carers, including:

- the types of care and support available
- how to access care and support, including eligibility criteria
- how to get financial advice about care and support
- local safeguarding procedures and how to raise safeguarding concerns or make a complaint
- rights and entitlements to assessments and care and support services
- personal budgets and all the options for taking a personal budget – for example, local authority managed, Individual Service Fund or direct payment.

1.2.2 Local authorities should ensure that information about care and support services is widely and publicly promoted – for example, in GP surgeries

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[5] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

[6] NICE is developing a guideline on provision of support for adult carers (expected publication July 2019).

and community spaces as well as in specialist services such as homeless health centres.

1.2.3 Local authorities should provide information about the circumstances in which independent advocacy is available, in line with the Accessible Information Standard, and how to access it.

1.2.4 Local authorities should provide comprehensive information about community resources and support, including voluntary organisations, user-led organisations and disabled people's organisations, and about available housing options.

1.3 Care and support needs assessment and care planning

1.3.1 Local authorities must, in line with the Care Act 2014, provide independent advocacy to enable people to participate in:

- care and support needs assessment and
- care planning and
- the implementation process and review

where they would otherwise have substantial difficulty in doing so.

1.3.2 People who are supported by an independent advocate during care and support needs assessment and care planning should have enough time with their advocate:

- for preparation before the assessment or care planning session
- to ensure they have understood the outcome afterwards.

Needs assessment

1.3.3 Local authorities must ensure that care and support needs assessment under the Care Act 2014 focuses on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve in their day-to-day life.

1.3.4 Care and support needs assessment should:

- involve the person and their carers in discussions and decisions about their care and support
- take into account the person’s personal history and life story
- take a whole family approach
- take into account the needs of carers
- take into account the person’s housing status, and where and who they want to live with
- be aimed at promoting their interests and independence
- be respectful of their dignity
- be transparent in terms of letting people and their families and carers know how, when and why decisions are made
- take into account the potential negative effect of social isolation on people's health and wellbeing[7].

1.3.5 Local authorities should consider the person’s preferences in terms of the time, date and location of the care and support needs assessment, and conduct the assessment face to face unless the person prefers a different method of assessment.

1.3.6 Local authorities should ensure that:

- the person is given details of the care and support needs assessment process and timescale at the start
- the person is given details of the nature and purpose of the assessment
- the person can have someone they choose to be present at the assessment
- the assessment uses up-to-date information and documentation about the person
- the person does not have to provide the same information in subsequent assessments.

1.3.7 If a person who uses services has caring responsibilities, their care and support needs assessment should take account of this. In line with the

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[7] This recommendation is adapted from the NICE guideline on home care.

Care Act 2014 they must also be offered a separate carer's assessment which should identify whether the person they care for is a carer themselves.

1.3.8 Ensure that care and support needs assessment documentation about the person is accurate, up to date and well maintained and clarifies what assessed needs will be met and how.

1.3.9 Offer the person a copy of any or all of the care and support needs assessment documentation. It should be shared with the person's carer if that is what they want.

Care and support plans

1.3.10 As part of care planning, consider identifying a named coordinator who is competent to:

- act as the first point of contact for any questions or problems
- contribute to the assessment process
- liaise and work with the person, their families, carers and advocates
- liaise and work with all health, social care and housing services involved with the person, including those provided by the voluntary and community sector
- ensure that any referrals needed are made and are actioned.

1.3.11 Build in flexibility to the care and support plan to accommodate changes to a person's priorities, needs and preferences – for example, by using direct payments (see recommendations 1.3.20 and 1.3.21) and agreeing a rolling 3-monthly budget so that people can use their money differently each week.

1.3.12 Local authorities and providers should ensure that the person's care and support plan includes clear information about what involvement from others (carers, family, friends and advocates) they want in their care and support, in line with the Care Act 2014. (See also recommendation 1.1.14.)

1.3.13 Ensure there is a transparent process for 'matching' care workers to people, taking into account:

- the person's care and support needs and
- the care workers' knowledge, skills and experience and
- if possible and appropriate, both parties' interests and preferences[8].

1.3.14 Ensure care workers are able to deliver care and support in a way that respects the person's cultural, religious and communication needs (see recommendation 1.1.11)[9].

1.3.15 Care and support plans should record and address the specific needs of people in relation to equality and diversity issues.

1.3.16 Care and support plans should be regularly reviewed, and include information on how and when these reviews should be carried out.

1.3.17 Care and support plans should include contingency planning and what to do in a crisis.

Personal budgets and direct payments

1.3.18 The local authority must include the person's personal budget in their care and support plan, in line with the Care Act 2014.

1.3.19 Local authorities should:

- inform people that they have the option to control their own funding to buy different sorts of care and support that meets their needs and chosen outcomes
- provide information, advice and support so that the person can choose which option suits them best
- give people the opportunity to exercise as much control as possible over the way they use any allocated funds to purchase a care package
- inform people of the different options for managing their budget.

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[8] This recommendation is adapted from the NICE guideline on home care.
[9] This recommendation is adapted from the NICE guideline on home care.

1.3.20 Local authorities should ensure that the direct payment process is:

- transparent about how the level of funding is decided
- straightforward
- accessible to all adults who receive social care and are eligible for local authority funding
- reviewed periodically to make sure that it is meeting the objectives of the care and support plan
- able to meet the legal obligations of the person receiving that direct payment if they employ personal assistants.

1.3.21 Local authorities should provide accessible information about direct payments, and peer support for people to use them. For example, this could be provided through user-led Centres for Independent Living.

1.3.22 In line with the Care Act statutory guidance, local authorities should support local services that provide peer support. Their contribution could include:

- financial support for local peer support services
- providing physical space for people who give peer support to hold meetings with people who use services
- helping peer support services with applying for grants for funding.

Personal assistants

1.3.23 If people have eligible needs that could be met by employing a personal assistant, the local authority should ensure that this option is discussed with the person and understood by them at the care and support planning stage.

1.3.24 In line with the Care Act statutory guidance, local authorities should ensure that support is available for people employing personal assistants, and that they are told about where to get support with:

- recruitment and retention of staff

- their role and responsibilities as an employer (for example, payroll, terms and conditions, redundancy and contingency planning).

1.3.25 Local authorities should consider the following to deliver support for people who employ personal assistants:

- user-led Centres for Independent Living
- other peer-support arrangements.

1.3.26 In line with the market shaping duty in the Care Act 2014, local authorities should work with people who use social care services and their carers to enable access to personal assistants. For example, this could be done by providing training opportunities for people who are interested in becoming personal assistants.

1.4 Providing care and support

Care and support in all settings

The following recommendations refer to care and support in all settings. For further detail about home care, please see the NICE guideline on home care for older people.

1.4.1 Service providers should foster a culture that enables practitioners to respect people's individual choices and preferences, in all settings where care and support is delivered, by:

- co-producing policies and protocols with people who use services and their carers (see recommendation 1.1.9)
- ensuring that there are open channels of communication between practitioners and people who use services
- using the communication methods that suit the person, in line with the Accessible Information Standard
- supporting people to take managed risks to achieve their goals – for example, taking part in hobbies or sports
- ensuring that there are systems in place for reporting concerns or abuse

- ensuring that practitioners have the time to build relationships with people
- training and supporting practitioners to work in this way, and checking they are doing so.

1.4.2 Practitioners working in all settings where care and support is delivered should ask the person using services, their carers, family, friends and advocates what name they prefer to be called, and use their preferred name.

1.4.3 Practitioners working in all settings where care and support is delivered should take time to build rapport with the people they support[10].

1.4.4 Practitioners working in all settings where care and support is delivered should respond flexibly to the priorities a person might identify each day. For example, a person might ask a home care worker to spend more time helping them get dressed and less time on other tasks if they have a special event to attend.

1.4.5 Day care and residential care providers should offer a choice of activities that are led by the person's needs, preferences and interests. Encourage people to take part by including activities that motivate them, support them to learn new skills and increase their level of independence. Recognise that preferences are not fixed and may change.

Continuity and consistency

1.4.6 Service providers in all settings, with oversight by commissioners, should review staffing numbers and skill mix regularly to ensure that staffing and skill levels are sufficient.

1.4.7 Commissioners and managers in all settings should ensure that there is continuity in care and support for people, including:

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[10] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

- ensuring that all practitioners involved with the person's care and support are familiar with how that person likes support to be given
- where possible, the same people are supporting the person
- if the same staff are not available, ensuring there are good handover arrangements
- ensuring that all staff supporting the person have similar levels of skills and competency
- using the same independent advocate where possible.

1.4.8 Providers and managers in all settings should ensure that:

- people are informed in advance if staff will be changed and
- any changes to care and support – for example, when visits will be made, are negotiated with the person.

1.4.9 Support people to make decisions about entering a new care setting or moving to a different setting. For guidance on transitions between particular settings, see the NICE guidelines on:

- transition from children's to adults' services for young people using health or social care services
- transition between inpatient hospital settings and community or care home settings for adults with social care needs
- transition between inpatient mental health settings and community or care home settings.

1.4.10 To support collaborative working between services, commissioners and managers should consider putting the following in place:

- a local policy for sharing information relevant to people's care within and between services in line with the Caldicott principles and the Health and Social Care (Safety and Quality) Act 2015
- joined-up policies, processes and systems.

Personal care

1.4.11 All practitioners providing personal care should ensure that personal care needs are responded to in a timely, appropriate and dignified manner in line with the person's wishes and their support plan – for example, making sure that people can go to the toilet when and how they want.

Promoting positive relationships between people who use services

1.4.12 Service managers and practitioners in day care and residential settings should promote a sense of community and mutual support – for example, by facilitating interactions and building social connections between residents through activities such as social events.

Residential settings

1.4.13 Practitioners and managers in residential settings should:

- ensure that the environment allows for people's preferences, self-expression and choice – for example, enabling people to have their own furniture and pictures
- support people to have control over their own medicines where possible (see the NICE guideline on managing medicines in care homes)
- deliver care and support in a personalised and friendly way
- give people privacy, especially when delivering personal care
- treat people with dignity and respect.

1.4.14 When designing residential services, providers should ensure that environments:

- create space where practitioners and residents can have positive interactions
- are welcoming to visits from family, friends, carers and advocates
- are stimulating, while not creating additional challenges for residents, including those with sensory impairments or dementia (for example, if the layout is frequently changed or there is poor lighting)

- enable positive risk taking (for example, being able to use outside spaces)
- support residents' autonomy (for example, by adapting kitchen facilities for people with physical disability).

1.4.15 Ensure that support in residential care is based on a good understanding of people's needs, including:

- providing practical and emotional support
- accommodating speech and communication needs
- helping people to maintain the personal relationships and friendships that are important to them
- supporting people to take part in activities and social groups that they want to be involved in, both in the residential setting and in the community
- viewing behaviour that challenges as communication
- providing access to community health teams and specialist support.

1.4.16 Practitioners should support people to participate fully in tasks and activities by ensuring that:

- the environment is conducive to their needs
- they have access to the equipment they need (for example, hoists or recliner chairs).

1.4.17 Managers should ensure that practitioners are trained to support residents to use any equipment they need.

End of life support in residential settings

For more information on end of life care, see NICE’s guideline on care of the dying adult.

1.4.18 Managers in residential settings should co-produce a policy on end-of-life care with people who use services and their carers. This should include information about:

- documenting treatment and care preferences at the earliest opportunity (including formal ways of documenting preferences such as Lasting Power of Attorney for health and care decisions, advance statements of wishes and care preferences or Advance Decisions to Refuse Treatment)
- a named lead in the residential setting
- training on supporting people and their carers at the end of their lives, tailored to different staff groups and updated regularly
- ongoing support to enable practitioners to support people near the end of their lives, including creative ways of engaging people in discussions (for example, opportunities to discuss end of life care with peers).

1.4.19 Managers in residential settings should consider making someone available who is independent and not part of the usual staff team to discuss end of life issues, for people who want to do this – for example, from an advocacy organisation.

1.5 Staff skills and experience

1.5.1 Have a transparent and fair recruitment and selection process that:

- uses values-based interviews and approaches to identify the personal attributes and attitudes essential for a caring and compassionate workforce and
- ensures that staff have the necessary language, literacy and numeracy skills to do the job[11].

1.5.2 Local authorities should ensure that people undertaking needs and eligibility assessments have the knowledge and skills to carry out assessments as described in recommendations 1.3.3 to 1.3.9.

1.5.3 Service providers should consider involving people who use services and their carers ('experts by experience') in the recruitment and training of staff. For example:

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[11] This recommendation is adapted from the NICE guideline on home care.

- being on interview panels
- contributing to development and delivery training
- helping to develop job descriptions
- supporting and training others to be experts by experience.

1.5.4 Consider providing opportunities for practitioners to learn from the personal experiences of all people who use services, in all settings where care and support is provided. This could be through:

- forums within residential and day care services
- audit, planning and evaluation of services
- practitioners being mentored by people who use services.

1.5.5 Service providers should ensure that practitioners are aware of the local arrangements for, and understand the function of, other services that they may need to work with, such as other health and social care service providers and services provided by the voluntary sector.

1.5.6 Service providers should provide opportunities for practitioners to take part in interprofessional learning and development.

1.5.7 Service providers should ensure that practitioners are able to use any equipment or devices people need – for example, hearing aid loops.

1.5.8 Service providers should ensure that practitioners are aware of issues relating to information sharing and confidentiality.

1.6 Involving people in service design and improvement

1.6.1 Local authorities must provide opportunities for people who use services to be involved if they want to in strategic decision-making about services, not just their own care and support, in line with the Local Government and Public Involvement in Health Act 2007. This should include involving people in:

- decisions about the way services are commissioned, run and are governed and

- checking that the service is delivering quality care and support.

Using people's views to improve services

1.6.2 All research into the views of people using care and support and their carers should be co-produced at all stages, including the research design, how it is carried out, and any resulting actions (for example, developing or refining quality indicators, developing monitoring tools or identifying gaps in services).

1.6.3 Commissioners and service providers should communicate clearly the outcome that any exercise to collect people's views is aiming to achieve and what will be done as a result.

1.6.4 Commissioners and service providers should consider using a range of approaches to gather views and experiences (for example, focus groups, interviews or observation in addition to surveys), and use evidence from a range of sources. This could include:

- the lived experiences of people who use services
- information from voluntary organisations that represent people who use social care services – for example, Healthwatch
- existing sources of information, such as complaints.

1.6.5 Local authorities should consider gathering and analysing evidence on people's experience of services in collaboration with other health and social care organisations serving the same populations to reduce duplication and ensure economies of scale.

1.6.6 Organisations conducting research should consider from the outset how to ensure that all groups are able to participate, including people who may lack capacity and people with different communication needs. This may involve adapting different research methods (see recommendation 1.6.4) or providing materials in a range of formats. If the participation or response rate for a particular group is low, the organisations should take action to improve it. This could include investigating what specific communication or cultural reasons may account for the low response and adapting materials or response formats to better suit that group.

1.6.7 Service providers should seek the views of people who use services about the extent to which the things that are important to them are being addressed. This should be done in such a way that the person feels safe to express their views, even if these are critical (for example, a care home resident may not want to give feedback directly to the manager).

1.6.8 Organisations or individuals conducting research or seeking feedback from people who use services should ensure that independent advocacy is available and offered when:

- this would help someone to take part or
- the person expresses a preference to use advocacy.

1.6.9 Service providers should consider employing people who use services to monitor people's experience of health and social care services, including conducting research. This could be done by:

- offering training to 'experts by experience' on how to conduct interviews with people who use services, including supporting them in applying ethical principles such as informed consent and confidentiality
- paying them to undertake exit interviews with people who have recently left a service or moved to another service[12].

1.6.10 Commissioners and providers should ensure that the results of research with people are used to inform improvements to services.

1.6.11 Commissioners and service providers should make available the results of research with people who use services, using approaches developed with people who use services. This should include:

- publishing the results
- giving feedback directly to people who took part

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[12] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

- making public how they have responded to people’s feedback – for example, by using ‘you said, we did’ tables or case studies.

Survey research

1.6.12 Consider using existing validated surveys before deciding to develop a new survey.

1.6.13 Local authorities should analyse the characteristics of people who did not or could not respond to surveys and:

- report on any under-represented groups in their published report of the survey and seek to understand the reasons for this
- develop ways to address these gaps in the future – for example, by considering alternative modes of response, such as a telephone response line
- ensure that information about under-represented groups is fed back to the survey designers.

1.6.14 Local authorities should ensure that people in their organisations who are responsible for interpreting and implementing survey findings have the necessary skills and capacity.

Terms used in this guideline

Care and support needs assessment

Under the Care Act 2014, local authorities must carry out an assessment of anyone who appears to require care and support. The aim of assessment is to understand the person’s needs and goals. After carrying out the assessment, the local authority consider whether any of the needs identified are eligible for support.

Care and support plan

A written plan after a person has had an assessment, setting out what their care and support needs are, how they will be met (including what they or anyone who cares for them will do) and what services they will receive.

Carer*

A person who provides unpaid support to a partner, family member, friend or neighbour who is ill, struggling or disabled and could not manage without this help. This is distinct from a care worker, who is paid to support people.

Centre for Independent Living*

A local organisation run by people with disabilities, that supports disabled people in their area to make choices about how and where they live their lives, with the assistance and support they need to live as independently as possible.

Commissioner*

A person or organisation that plans the services that are needed by the people who live in the area the organisation covers, and ensures that services are available. Sometimes the commissioner will pay for services, but not always. The local council is the commissioner for adult social care. NHS care is commissioned separately by local clinical commissioning groups. In many areas health and social care commissioners work together to make sure that the right services are in place for the local population.

Communication aid

A communication aid helps a person to communicate more effectively with those around them. This could range from a simple letter board to a more sophisticated piece of electronic equipment.

Co-production*

When a person who uses services is involved as an equal partner in designing the support and services they receive. Co-production recognises that people who use social care services (and their families) have knowledge and experience that can be used to help make services better, not only for themselves but for other people who need social care.

The Think Local Act Personal's 6 principles of co-production are:

- recognising people as assets
- building on people's capabilities

- developing 2-way, reciprocal relationships
- encouraging peer support
- blurring boundaries between delivering and receiving services
- facilitating rather than delivering.

Day care services*

Opportunities for people to do things during the day, while living in their own home. These may include social activities, education, or the opportunity to learn new skills. What the local council offers will vary, depending on what a person needs and what is available in that area. People who use services may have to pay something towards the cost.

Home care*

Care provided in a person's own home by paid care workers to help them with their daily life. It is also known as domiciliary care. Home care workers are usually employed by an independent agency, and the service may be arranged by the local council or by the person that needs care (or someone acting on their behalf).

Information sharing

Information sharing refers to the sharing of information about people who use services within and between organisations. Personal information can be shared within or between organisations with the person's consent, or if it is believed to be in the public interest. See the 7 golden rules of information sharing.

Joint commissioning*

When 2 or more organisations in a local area – usually the NHS and local council – work together to plan services to meet the needs of people who live in the area. Together the commissioners plan what kind of services should be available, who should provide them and how they should be paid for.

Named care coordinator

The person in an organisation who is responsible for coordinating support for the person and their family if needed – for example, a named social worker or a nurse. The coordinator role refers to a function and not a post.

Peer support*

The practical and emotional help and support that people who have personal experience of a particular health condition or disability can give each other, based on their shared experience. People support each other as equals, one-to-one or in groups, either face-to-face, online or on the telephone.

Person who uses services

A person who receives services from a care and support provider. It is often preferred to the term ‘service user’.

Personal assistant*

Someone the person using services chooses to employ to provide the support they need, in the way that suits them best. This may include cooking, cleaning, help with personal care such as washing and dressing, and other things such as getting out and about in the community. A personal assistant can be paid through a direct payment.

Personalised care

An approach that puts the person receiving care and support at the centre of the way care is planned and delivered. It is based around the person and their own needs, preferences and priorities. It treats the person receiving services as an equal partner, and puts into practice the principle of 'no decision about me without me'.

Practitioner

Any worker who provides support to the person and their family and carers. Practitioners include people working in all settings and in different roles – for example, social workers, health professionals and care home staff. Practitioners could also include those with designated roles, such as care coordinators or key workers.

Residential settings

Accommodation where care and support are provided by staff. These settings can be run by the private sector, voluntary sector or local authority. Residential settings can include residential care homes and nursing homes and also include supported living.

Supported living*

Accommodation and support that enables adults with disabilities to live in their own home, with the help they need to be independent. It allows people to choose where they want to live, who they want to live with, how they want to be supported, and what happens in their home.

Voluntary sector*

Also referred to as ‘voluntary and community social enterprise sector’ (VCSE). It refers to organisations that are independent of the government and local councils. Their role is to benefit the people they serve, not to make a profit. Social care services are often provided by VCSEs, by arrangement with the council or with the individual. Some are user-led organisations, which means they are run by and for the people the organisation is designed to benefit – for example, disabled people.

*The source of these definitions is the Think Local, Act Personal’s Care and support jargon buster. Also see the jargon buster for other social care terms.

2 Research recommendations

The Guideline Committee has made the following recommendations for research.

2.1 Methods and approaches for gathering the experiences of people who use adult social care services

Research question

When conducting research for the purposes of service improvement, what research methods are acceptable, appropriate and effective in meaningfully gathering the views and experiences of people who use services?

Why this is important

Current research methods for gathering the views and experiences of people who use services commonly include standardised surveys and measures (for example pain-reported outcome measures [PROMS]; NHS and social care: public perceptions surveys; The National Adult Social Care User Experience Survey). However, the evidence reviewed for this guideline suggests that measures of this kind may have limitations in terms of how comprehensive and representative these people are who are typically willing and able to respond to these kinds of self-completion postal surveys. This means that some people's views and experiences of social care may not be included in surveys designed to support service improvement. Further research is needed to:

- Determine the extent to which frequently used research methods meaningfully engage people and provide an accurate picture of their views and experiences.
- Develop and test new or innovative methods for gathering views and experiences. This could include narrative methods and the use of technology such as apps. The methods would be compared in relation to how well they were able to provide accurate and detailed information on people's views and experiences of care and support.

Criterion	**Explanation**
Population (Who the research would be with?)	Adults aged 18 or over and in receipt of social care
Intervention (What would the research be testing?)	Methods and approaches for gathering the views of people who use services
Comparators (What would we compare the intervention to?)	Current standardised methods for gathering views of people who use services
Outcomes (What outcomes would the research measure?)	Internal and external validity of research methods (for quantitative methods this may include instrument reliability, survey response rates, representativeness, non-response bias, costs, measurement of outcomes important to people who use services; for qualitative methods this might include the richness of data diversity of views obtained). Feasibility and cost effectiveness of research methods Acceptability of research methods to people who use services
Study design	Primary research is needed to pilot and test new ways of gathering service user view and experiences. This should take a co-productive approach, involving service users in the design, delivery and analysis of developing methods. Comparative evaluation which determines the relative effectiveness of different approaches to gathering the views and experiences of users of social care services in terms of providing a representative, inclusive,

	accurate and detailed account of their views and experiences of care and support.
Timeframe	No specific timeframe required.

2.2 Co-producing research into the views and experiences of people who use services

Research question

What approaches have been shown to work in supporting the co-production of research for the purposes of service improvement with people who use services?

Why this is important

Co-production is a key concept in the development of public services (Co-production in social care: What it is and how to do it, Social Care Institute for Excellence) and there are many examples in practice that highlight how individuals and communities can positively shape the way that services are designed, commissioned and delivered (Co-production in commissioning, Think Local Act Personal 2015). Co-produced research on the views and experiences of people who use services is a potential means of improving services. Co-producing all stages of the research process with people who use services is an important principle, which may signpost pertinent issues and questions that would have otherwise been neglected. However, there is little published evidence about how to put the principle of co-production in to practice in research, although it appears that there may be good practice occurring within the sector.

Criterion	**Explanation**
Population	Adults aged 18 and over and in receipt of social care
Intervention	Co- production of research for the purposes of service improvement
Comparators	N/A
Outcomes	Acceptability of methods to people who use services Internal and external validity of research methods
Study design	A call for evidence is proposed as a first stage, especially as organisations who are active in this area may not have published widely in peer reviewed journals and standard research circles. The evidence gathered from this process could then be used as a framework for subsequent collaborative action research. Action research would involve both researchers and service users and their carers working collaboratively on all stages of research from

	developing concepts and identifying issues that need to be explored to the design and delivery of research. A continuous process of user feedback and reflection would help to identify follow-up actions that would be investigated and tested until the
Timeframe	No specific timeframe required.

2.3 Identifying barriers and enablers to using the views and experiences of people who use services to improve services

Research question

What are the barriers and enablers to gathering, synthesising and applying data on the views and experiences of people who use services for the purposes of service improvement?

Why this is important

There are several examples of data gathering processes designed with the purpose of improving services – for example, annual mandatory local authority surveys, audit, and small-scale consultation at the individual organisation level. However, little is known about how the data from these exercises are translated into change and improvement in services, including:

- what capacity is needed within organisations to gather data and make use of it, and whether this is present?
- what factors determine whether the findings of research are implemented in practice?

Criterion	**Explanation**
Population	Commissioners and service managers of adult social care services
Intervention	Methods used within organisations to gather, analyse and make use of views and experiences data gathered from people who use services
Comparators	N/A
Outcomes	Change and improvement in service design and delivery
Study design	Qualitative research (for example, interviews and focus groups) regarding barriers and facilitators to gathering, synthesising and applying data on the views and experiences of service users for the purposes of service improvement.
Timeframe	No specific timeframe required.

2.4 Use of technology in providing care

Research question

What are the views and experiences of people who use adult social care services on assistive technologies?

Why this is important

Assistive technology is one means by which social care services can help people to maintain independence. These technologies include a wide range of devices, ranging from simple, low-cost devices such as pendant alarms, to more intricate home monitoring systems using electronic information and communication technology – for example, integrated systems of sensors, alarms and remote monitoring. Across all population groups, there is a paucity of evidence about how acceptable assistive technology is to people who use services, and the impact of the technology on their satisfaction with services. Issues that could be explored include the extent to which the technology is and can be personalised, anxiety that it may be used to scale back services and reduce human contact, loss of confidentiality where personal information is shared, and ethical questions around privacy and surveillance.

Criterion	**Explanation**
Population	Adults aged 18 and over and in receipt of social care
Intervention	Assistive technologies (for example, pendant alarms, sensors, alarms, remote monitoring)
Comparators	Delivery of care without assistive technologies Alternative assistive technology
Outcomes	Acceptability of assistive technologies to people using adult social care services. Wellbeing and quality of life (related to health, mental health and social wellbeing). Choice and control.
Study design	Studies using a comparative design with quantitative variables to measure the above, or qualitative studies of the views and experiences of people who use services.
Timeframe	No specific timeframe required.

3 Evidence review and recommendations

This guideline was developed using the methods and processes set out in Developing NICE guidelines: the manual (2014). The nature of the guideline topic required some adaptation of these methods, to accommodate the volume and nature of the evidence. Methods were agreed with NICE during the process and are set out below.

For more information on how this guideline was developed, see Appendix A.

Overview

The review explored 4 questions relating to people's experience of adult social care services:

1. Which aspects of the experience of using adult social care services are positive or valued by people who use services?

2. For people who use adult social care services, what are the barriers related to improving their experience of care?

3. For people who use adult social care services, what would help improve their experience of care?

4. What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?

We conducted a single comprehensive search, which encompassed all questions. This search was not limited by study design and included a range of terms to cover all populations across health and social care included in the guideline scope. Further detail on this search is provided in Appendix A. All results (n=36,520) were imported into EPPI-Reviewer, a software package developed to support systematic reviews. A de-duplication tool removed 12,322 study entries as duplicates, leaving 24,198 studies, which were manually screened based on the title and abstract against the inclusion criteria defined in the review protocols.

Included studies were rated for internal and external validity using three levels: high (++), medium (+) or low (-). The critical appraisal of each study considered characteristics of the study's design, and the internal validity of the study execution, that is the extent to which the study is able to measure what it aims to measure, and the external validity, that is the generalisability of the study findings to the population in the guideline scope. A judgement was made for an overall rating of the study (++, + or -), taking into account the ratings for internal and external validity.

A cut-off year of 2000 was chosen to include those studies that were most likely to be generalisable to the England and Wales policy and legislative context, and to manage the volume of evidence. Two significant policy and legislative changes at this time were the Health and Social Care Act 2001 and Valuing People 2001 that were intended to change the way people experienced health and social care services.

The evidence tables (Appendix B) provide details on each included study: information about the study's focus and context, design and findings, as well as details on critical appraisal, which underpins the overall quality ratings.

Economic studies have not been included as no studies were found on the cost-effectiveness of methods to gather people's views and experiences and the impact this has on service improvement.

Methodology

Sampling of studies for inclusion for review questions 1 to 3

Title and abstract screening for review questions 1 to 3 identified an extremely high volume of potential studies. To address the volume of data, research literature identified from the initial screening on title and abstract were mapped on the key characteristics of the study in terms of quality, setting and participants. Studies were mapped against:

- A framework for determining best available evidence in terms of the "richness" of views and experiences to answer review questions 1 to 3
- Settings where care was delivered

- A scoping framework derived from three existing reviews of dimensions of service users' experience
- Study population characteristics.

The mapping stage enabled the reviewing team with advice from the Guideline Committee to stratify the sampling of studies to ensure the even coverage of views and experiences across a range of settings and populations.

More information about each of the dimensions of the mapping is provided below:

Coding studies on title and abstract by 'richness' of qualitative data and if the qualitative data has direct reports from service users

It was important to the Guideline Committee to focus on studies that were designed in such a way that focused on the views of voice of the participants and reported views and experiences in the participants' own words. This is because service users have direct experience of using social care - experience which may not be represented as clearly if sought from indirect sources such as professionals, who may have their own perceptions about what users need. It was considered such studies would inform questions 1–3, which are about the views and experiences of adults using social care services.

The review team developed a coding tool which would allow for the selection of qualitative studies against a hierarchy of qualitative study designs, to identify those studies that used qualitative methods of data collection that were most likely to elicit data rich in views such as one-to-one interviews, unstructured or semi-structured interviews, and studies using data analysis methods most likely to elicit rich qualitative data, for example adopting a grounded theory approach or a phenomenological approach. In addition, studies were coded on the basis of whether they were quoting directly from users of services rather than through carers or practitioners. Studies were then categorised as being either 'gold' or 'silver' standard.

'Gold standard' studies were defined as theoretically driven or those that employed purposive sampling or use theoretically driven analysis. Examples of such studies include those taking a grounded theory approach or phenomenological approach. Within this category distinction was made between:

- Direct user views – indicative the full text is likely to be rich in narrative quotes directly from users
- Indirect – indicative the full text is likely to be mostly proxy views such as from informal or paid carers.

'Silver standard' studies were those in which the sampling or analysis was not theoretically driven (for example, done for practical reasons), or was unclear and unstated, but included user views. Again a distinction was made between:

- Direct user views – indicative the full text is likely to be rich in narrative quotes directly from users
- Indirect – indicative that the full text is likely to be mostly proxy views.

Examples of ‘Silver’ studies include surveys with very few verbatim quotes or video evidence rich in user views but lacking in methodological rigour.

Only papers that were rich in direct user views were included. This could be either gold or silver standard.

Coding studies by settings

At the beginning of review work, a broad range of settings was considered but, in consultation with the Guideline Committee, these were focused to four main settings: hospital, community, own home and residential care. At the start of the review process, there was concern from the Guideline Committee that many studies were about residential care, but subsequently this was addressed by sampling studies across a range of settings to ensure a more balanced representation of views and experiences of social care in different settings.

Applying a scoping framework to identify themes

The review team suggested coding studies using a scoping framework derived from three existing reviews of service users experience to compare the scope and themes of dimensions of service experiences.

This information could then be used to both describe the studies and as a means of prioritisation, so that when a theme became saturated, no further studies in that theme were included.

A framework was developed by the review team and was condensed to 6 category labels of service users experience from 3 primary sources:

- Think Local Act Personal 'Making It Real' statements.
- Picker principles of patient-centred care statements.
- The themes used in NICE clinical guideline on Patient experience in adult NHS services (which were themselves derived from a thematic review of patient experience research).

Dimensions of experience that were common to the three sources were:

- respect, dignity and control
- personalised support
- information and communication
- active participation in lived experience of care
- continuity of care and transitions (including access to care)
- support for people's needs.

Study population characteristics

Studies were also mapped against the following groups identified in the study. This was to ensure groups with 'protected characteristics' in the Equality Impact Assessment were being included with the studies being reviewed.

- Black and minority ethnic (BME)
- Condition specific illnesses, for example asthma
- People with dementia
- Disabled people
- Homeless
- End of life
- People with learning disabilities
- Lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI)
- People with a mental health condition
- Older people
- Sensory impairment
- Service users (all)

- Substance abuse
- Young people
- Personal assistants (introduced after GC6 as a gap identified from evidence presented at GC6).

This mapping by population group provided valuable feedback to the Guideline Committee process and allowed for the identification of groups of interest to the Guideline Committee, particularly where the Guideline Committee considered that evidence was weaker or that some groups may be at greater risk of poor outcomes.

This evidence from qualitative studies were further organised into themes of common and shared experiences for each of the review questions and presented formed the evidence statements.

Conducting additional analysis in relation to particular groups

After initial presentation of the evidence for review questions 1 to 3, the Guideline Committee highlighted three areas in which they thought that evidence was lacking, or was of particular importance:

- Studies relating to people in residential care settings
- Studies of people with learning disabilities, including autism
- Studies of people hard of hearing, with multiple sensory impairments
- Studies of people who used Personal Assistants (PAs).

In the absence of high-quality evidence on these groups (gold standard), the Guideline Committee suggested including lower quality evidence (silver direct standard), on the understanding that the strength of evidence may be weaker. The views data from the weaker study designs were supplemented by the Guideline Committee expertise and consensus decision making.

Weaker study designs included video evidence which often did not report on the methods, but did include people who spoke about their experiences of social care in their own words. The decision to use video evidence was aligned to the focus on evidence based on direct service user views. The Guideline Committee identified video evidence as a good source of direct views. Additional searches for video evidence were therefore conducted.

All video evidence reviewed was subjected to the same scrutiny as the review data. Video data were quality appraised using the qualitative study critical appraisal tool in the same way as textual evidence by using the written, verbatim transcripts. Therefore only videos with transcripts were considered and the text data extracted for qualitative themes. All videos were screened on ‘richness of data’ and all included video evidence was coded silver direct quality.

Presentation of evidence synthesis

Individual narrative summaries for each study were presented. This evidence from individual studies was then organised into inductive themes of common and shared experiences for each of the review questions and formed the evidence statements presented to the Guideline Committee.

Economic analysis

The economic plan prioritised review question 4 (What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?) for additional economic analysis.

It was planned that any additional analysis would be a costing exercise on the different methods of collecting people’s views and experiences of their care. Ultimately, this analysis could not be taken forward because we were unable to identify a specific survey or surveys as the basis for analysis, without which, a costing analysis was not possible. Instead, the economists provided expert witness testimony from an academic at PSSRU to explain the factors that would influence the cost-effectiveness of different survey methods.

Review of related guidelines

The Committee reviewed recommendations in guidelines which overlapped in terms of review population and scope. The recommendations were adopted or adapted using the process set out in the NICE guidelines manual. In particular, detailed review was undertaken early on the process of two guidelines relating to service user experience: the NICE guideline on Patient experience in adult NHS services: improving the experience of care for people using adult NHS services and Service user experience in adult mental health services: improving the experience of care for people using adult NHS mental health services. This was to avoid duplication of recommendations with these guidelines.

The presentation of evidence in this section

Review questions 1 to 3 were about the views and experiences of service users, prioritising original research rich in direct user views. Review question 4 is based on studies measuring effectiveness and cost-effectiveness.

Section 3.1 covers review question 1, which examines the views and experiences of adults in terms of what aspects of social care they value or find positive across all four settings: hospital, community, own home and residential care. Section 3.2 addresses the views and experiences of people using adult social care, with particular emphasis on the barriers and facilitators (review questions 2 and 3 respectively) related to improving their experience of care in these settings. Section 3.3 focuses specifically on the barriers within residential care because this topic was identified by the Guideline Committee as an area of particular concern, since residents can be both excluded from research and can also be at particular risk of poor care. Sections 3.4 to 3.6 examine the views and experiences and barriers and facilitators for good care for groups identified by the Guideline Committee for additional analysis. Section 3.7 covers review question 4 and is based on original studies measuring effectiveness and cost-effectiveness of methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services.

3.1 Views and experiences of valued and positive aspects of adult social care

Introduction to the review question

Review question 1 aimed to explore the views and experiences of adults who use social care in terms of what aspects of social care they value or find positive. It aimed to explore views within the context of four main settings: hospital, community, people's own homes and residential care.

Review question

1. Which aspects of the experience of using adult social care services are positive or valued by people who use services?

Summary of the review protocol

Review question 1

This review question sought to identify evidence about what people who use adult social care services value as positive aspects of their experience, including what people think works well or contributes to a positive experience.

This question therefore sought to identify qualitative studies, mixed-methods studies and systematic reviews of qualitative or mixed-methods studies.

Population

Adults aged 18 or over who use social care services.

Intervention

Experience of social care services.

Setting

All UK settings where care is delivered.

Outcomes: Qualitative themes

1. Wellbeing and quality of life (related to health, mental health and social wellbeing)
2. Engagement with services and care, including understanding relevant care and management issues where appropriate
3. Choice and control
4. Satisfaction of people who use services (including carer, family and advocate perceptions of how satisfied the people who use services are)
5. Perceived and objectively measured independence
6. Ability to carry out activities of daily living with or without support
7. Continuity of care
8. Participation in social and community activities, including training and education, paid and unpaid employment
9. Resource use

10. Security and personal safety

See appendix A for full protocols.

How the literature was searched

Electronic databases in the research fields of social care, health, and social sciences were searched using a range of controlled indexing and free-text search terms combining the four concepts of:

- Views and experiences – including: views, experience, preference, perspective, satisfaction, dissatisfaction, feedback, learn, attitudes, expectation, complaint
- Setting (social care services) – including: social care, social provision, social service, community, residential, home, personal budget, direct payment, care plan
- Population (adults) – including: adults, older people, frail, elderly, homeless, disabled, disability
- Study type and outcomes – including: quality studies, evaluation studies, measures or outcomes, economic studies.

The search was restricted to human studies in the English language and published from 2000. A cut-off year of 2000 was chosen to include those studies that were most likely to be generalisable to the England and Wales policy and legislative context, and to manage the volume of evidence. Two significant policy and legislative changes at this time were the Health and Social Care Act 2001 and Valuing People 2001 that were intended to change the way people experienced health and social care services.

The search aimed to capture both journal articles and other publications of empirical research. Additional searches of websites of relevant organisations, and research archives or databases, were undertaken to capture literature that might not have been found from the database searches.

We additionally searched databases that contained a range of relevant video evidence of people's experiences of social care. The decision to use video evidence was aligned to the focus on evidence based on direct service user views. The Guideline Committee identified video evidence as a good source of direct views. Additional searches for video evidence were therefore conducted. In order to ensure we could conduct data extraction in a consistent manner, we sought databases which contained a range of relevant video evidence accompanied by transcripts. This included the Social Care Institute for Excellence (SCIE), Social Care TV and Think Local Act Personal (TLAP) video collection. Videos were screened against the inclusion criteria from the review protocol and potentially relevant videos were then mapped against setting and priority scoping framework areas and the full content reviewed. Videos were included on the basis that they provided illustrative examples of views from priority population groups.

Economic evidence was searched for as part of the single search strategy, and included searching within the economic databases such as the NHS Economic Evaluation Database (NHS EED) and the Health Economic Evaluations Database (HEED).

A call for evidence from stakeholders, providing an opportunity for any groups or organisations to submit relevant evidence, was also carried out at the beginning of the review.

Guideline committee members were also asked to alert the NICE Collaborating Centre for Social Care to any additional evidence, published, unpublished or in press, that met the inclusion criteria throughout the review.

The database and website searches were undertaken in March 2016. Update searching of the bibliographic databases searches took place in January 2017. When the update searches were run, an adjustment was made to the original search strategy to include the term ‘disabled’ in the population segment of the search.

See appendix A for full details of the search.

How studies were selected

Search outputs (title and abstract and only) were stored in EPPI Reviewer 4 – a software program developed for systematic review of large search outputs – and screened against the inclusion and exclusion criteria defined in the scope, which were as follows:

- Exclude on language. Not published in English.

- Exclude on date. Studies published prior to 2000 will be excluded. Systematic reviews where fewer than 80% or more of included papers meet our inclusion criteria – this includes publication date.
- Exclude on country. This study is not set in the UK.
- Exclude on population 1. Participants are less than 18 years of age.
- Exclude on population 2. Study is with carers (unless they are being used to give proxy views on behalf of people who use services).
- Exclude on intervention. For RQ1–3: Not about user views of services – what is valued, or barriers or facilitators to using services.
- Exclude on setting. Not in one of the settings where adult social care is delivered as specified in the protocol.
- Exclude on outcomes. Not about views and experiences of services
- Exclude on evidence type. For example, opinion pieces.

There were 1,611 studies that met the initial inclusion criteria and were included based on the title and abstract. Studies were then mapped against the criteria outlined at the beginning of Section 3 and sampled accordingly. Full texts of included studies were retrieved and screened against the inclusion criteria. Following sampling and full text screening, 16 studies were selected for inclusion.

See appendix B for full critical appraisal and findings tables.

Narrative summary of the evidence

Barnes C and Mercer G (2006) Creating user-led disability services in a disabling society.

Methods: Data collection from the nine case study sites included collection of documentary evidence (for example, mission statements and minutes of AGMs); and semi-structured interviews with staff and users. Data from users was collected as part of stage 3 of the project.

Data: Service user views from disabled people of user-led services contrasted with mainstream provision.

Country: Scotland, Wales and England.

Setting: A range of settings in the statutory, voluntary and private sector, including day centres and care homes. Also included are people's own homes.

Scoping framework areas: Respect, dignity and control; personalised support; information and communication; active participation in lived experience of care; care and support for people's needs.

This report presents analysis of a study rated high (++) quality from chapter 7, which draws from material from the first national study (Creating Independent Futures 2000) of user-led services. It discusses users' experiences using mainstream, community-based support services and contrasts this with disabled people's experiences of user-led services, with in-depth examination of the issues specific to user-led services that users believe distinguish them from mainstream provision.

The research project was initiated by the British Council of Disabled People (BCODP) Research Committee in 1998 and developed with the National Centre for Independent Living (NCIL). Its main aim was to assess the development of Centres for Independent Living (CILs) and similar user-directed organisations (Authors, p63). The service user interviews were conducted in 2001 as part of stage 3 of the project.

Sample size: 76 disabled people of whom nearly half were aged 35 to 54, four people aged 18 to 24 and five people aged over 65. Sixty-five people described themselves as having a physical impairment, 8 people reported emotional distress, 8 people had learning difficulties and 8 people had sensory impairments. Thirty-six people lived with their partner, family or friends, while 33 people lived alone and six lived in residential homes.

Analysis: Qualitative data from the interviews was analysed using the 'constant comparison' approach (Glaser and Strauss 1967). Categories were identified and two researchers examined the data to identify the existence and consistency of key themes across participants and research sites (p66). The researchers aimed to ensure that the research should be accountable to disabled people; therefore data analysis and drafts were shared with representatives of disabled people's organisations and the advisory group for their comment (Authors, p56).

Findings

Services accessed by disabled interviewees covered the statutory, private and voluntary sector. Most (68) of the sample of 76 individuals were still accessing services from local authority (LA) social service departments, including input from a social worker or case manager, home adaptations, home helps and day centre placements. Generally, individuals criticised these mainstream organisations for not being responsive, while CIL organisations were seen as significantly more responsive to people's needs, despite their lack of resources.

1. Mainstream provision

Assessments

Professionals led most assessments and most participants felt that these were not personalised, confirming for participants the importance of moving towards self-assessment.

'They just don't work to the services that you require...they suit themselves. They don't listen...Mind you, I suppose that they are short of staff and that's their way..."look we've got other people to attend to", but that's not what people want to hear’ (Participant 1, p117).

'It was a fight to get any sort of assessment to begin with. Their assessments were budget led’ (Participant 2, p117).

Home-helps

The limitations on what home-helps could do was a significant anxiety, with many interviewees talking about difficulties caused, especially relating to lifting and handling and domestic tasks. Reliability of home-helps, including agency staff and volunteers, was particularly problematic:

'...there might be 400 of you in an area and 40 people coming out to do the care. So you have to allow for this and be flexible. What happens in reality sis that you're up at half past seven (in the morning) waiting for your care workers and sometimes at a quarter to one in the afternoon you are still sitting there waiting for her' (Participant 2, p118).

This situation was especially challenging for people whose health conditions fluctuated from day to day, for example, those with multiple sclerosis or severe emotional distress, as the level of support needed would vary accordingly.

High staff turnover and variable quality of support were other issues that caused anxiety to care users:

'You didn't know who was coming to see you and a lot of different people come and they would come in and tell you what they would do, they didn't know what to do with me, how to lift me or anything' (Participant 3 , p119).

Lack of control

Several interviewees felt that they had no control but that they were expected to be grateful for services:

'There was no control...I was very much worked on, I was an object more than a subject' (Participant 4, p119)

Complaints

Participants also pointed out that complaints were often not dealt with properly and individuals who raised complaints were often labelled as 'trouble makers' (Authors, p119).

'You're put down as a whiner, or you're a moaner, the fact that you mightn't have had a shower for three or four days – "well, it doesn't really matter dear, you're not really going anywhere today, are you?"' (Participant 2, p120)

2. Accessing user-led services

Referrals

The authors note that it is significant that most of the people interviewed were signposted to user-led organisations by professionals in statutory services. Referrals were proportionately higher in those areas where links were strong between user-controlled organisations, local social services department or the health authority, for example in Cardiff, Glasgow and Surrey:

‘I would say that that particular office at social services was quite proactive in helping me get in touch with the direct payment scheme.' (Participant 5, p120)

But there was no automatic system of referral by health authorities or allied health professionals for disabled people:

‘When I started to become ill and went to the hospital, he [the consultant] gives you a prognosis, I was left absolutely devastated. There was no information in the hospital whatsoever, and I wasn't in a state to ask. Basically I went home not aware of any group whatsoever...You're by yourself, you don't know where to go' (Participant 6, p123).

Use of services and choice and control

Two main themes were identified in comparisons between professionally led and user-led organisations: choice and control. Participants were explicit about the fact that user-led organisations offered them more choice of services and increased control over how these services were delivered:

‘I have transferred from a social services' help at home to a direct payment scheme via the [user-controlled organisation]. We were struggling with the kind of help we were having... [The independent living support worker from the organisation] came to see us with my social worker. We discussed the whys and wherefores, and we thought we would at least attempt to use this direct payment scheme...From day one the impact was just totally different. It totally turned our lives around' (Participant 7, p124).

Support groups

Some people used direct payments from other agencies but attended PA employers' support groups run by the case study organisation:

'Nobody was able to help me with the Independent Living [Fund]...I was at my wits end when I discovered the [CIL]. M... [a disabled support worker] has been exceptionally helpful. I was over today to talk to her about the payment of Income Tax and National Insurance. I actually had to call the taxman. He didn't know anything about carers, about people like me employing carers...' (Participant 8, p125)

Use of direct payments

Participants regularly pointed out that social workers and other professionals questioned the competence of disabled people applying for direct payments:

'I went to the social work side and it went so far, and basically it was binned at a certain level. I didn't get the support to follow it through, or the information. So I went back and challenged them and came down here to the CIL...and that's why I've been coming on the training schemes...They bring you up to speed with what's necessary...How do you handle your personal assistants? How do you handle your payroll?.The CIL it can keep you totally on the right track...' (Participant 9, p125)

Information

Access to information was a problem, especially for people with newly acquired impairments:

'It's the "catch-22" situation, in as much as when you need it, when you become disabled or incapable of performing certain functions, it becomes harder and harder to obtain information...' (Participant 10, p126)

The authors report that 49% of the participants had sought out information from the case study organisations.

Training

Nearly half of the participants saw themselves as both users and members of their local CIL. Training facilities and courses were offered by all the case study organisations:

'The training I received enabled me to be a proficient deliverer of Disability Awareness or Equality Training...' (Participant 11, p127)

Counselling and peer support

The need for counselling was particularly valued by those disabled people who had recently acquired their impairment or recently become aware of disability issues:

'When I came here they gave me confidence to carry on...I know there's a support group here and someone I can come and talk to whereas before I didn't...' (Participant 6, p128)

Formal and informal peer support provided by other disabled people active in the case study organisations was identified as helpful in reducing social isolation (Authors, p129).

Sensitivity to need

Participants felt that user-controlled organisations were much more sensitive to their specific needs:

'When I was on my own without a PA or somebody I could exchange information or confidences with...Well I would have either become a basket case or, ...a suicidal case...Psychologically the [CIL] gives the individual a sense of identity and a sense of which places to go for help. So it certainly is a lifeline in that respect' (Participant 5, p129).

3. Wants and aspirations

Participants often said there was a problem with the lack of information about the benefits of user-controlled services and the organisations providing them:

'I certainly think they could improve by making more people aware that the place is here...People like myself, who become disabled, you don't know who to turn to...' (Participant 6, p131)

Some participants were very worried that CILs were not attracting younger disabled people. Other problems mentioned by participants was accessibility of buildings used by CILs, location and problems travelling by public transport, and staff shortages which could impact on the efficiency and effectiveness of services (Authors, p132).

Considerations: The authors point out that the sample from the 9 case study sites was not representative. As membership and user lists are confidential, researchers resorted to using a range of methods to recruit participants, including sending invitations to potential participants in local newsletters, sending letters directly to individuals in organisations, or approaching potential interviewees for names of individuals who might be interested (p66). Chapter 4 briefly describes the characteristics of the participants and the 9 case study organisations. However, the user views presented do not distinguish between this diversity.

Cameron A, Abrahams H, Morgan K et al. (2016) From pillar to post: homeless women's experiences of social care.

Methods: Small-scale longitudinal study over two years with three rounds of interviews over the duration of the study period.

Data: Views of homeless women about particular events in their lives, their current living arrangements and how their experiences and needs, including for social care, changed over time.

Country: England.

Setting: Range of settings including homeless accommodation, and specialist services such as mental health or drug and alcohol services.

Scoping framework areas: Personalised support; information and communication; continuity of care and transitions; care and support for people’s needs.

This report presents data from the TARA project, a two-year longitudinal study based in a large English city. The study rated high (++) quality tracked a group of homeless women (without secure housing) and women at risk of homelessness (from tenancy breakdown) to determine how their experiences and needs evolved over this time. The aim was to increase awareness of their needs, including their social care needs, as a means to recognise how best to support women to access and sustain engagement with support services.

Sample size: Despite the intention to recruit 40 women, the final sample was 38. At the second stage, six months later, 28 women were re-interviewed, and at the final stage, six months later, 22 women were interviewed. The sample ranged in age from 19 to 59. Most women described their ethnicity as white British (27), 4 women described themselves as white European, 2 as black African and 5 as mixed race.

Analysis: Interviews were digitally recorded and transcribed. Transcripts were analysed thematically using predetermined codes derived from the existing research literature and supplemented with further codes as the analysis progressed (Flick 2009). Sometimes, codes overlapped (Gilbert 2008), reflecting the interrelated nature of events and feelings described by participants. Coded transcripts were cross-checked by researchers on the team to ensure consistency. Computer-assisted analysis software was used to manage the data.

Findings

This study highlighted the disorganised nature of support for homeless women. There were also positive examples of person-centred services. The findings are summarised under the four headings below.

1. Supporting women

Many of the women had multiple key workers. One woman, said how she was ‘getting all the support I need’ from workers at a community-based drug treatment service for black, Asian and minority ethnic adults as well as from a generic drugs project and a housing association (Participant 1 , p348).

But many women found it difficult dealing with multiple services in parallel.

‘… I think it’s easier just to have one person to talk to’ (Participant 2, p348).

In terms of what individuals felt worked well about key workers, another woman explained how she valued the reliable and non-judgemental support from workers based in a voluntary organisation.

'Cos I just gave up, you know. But they’ve never given up on me, even though I’ve made mistakes… and I’ve had my relapses and I’ve had whatever – their door’s always open to me’ (Participant 3, p348).

Participant 2 said to the researchers that having a worker of a similar age who had similar experiences was very important to her.

Other women valued having a key worker who took a holistic, person-centred approach. A woman explained how her worker from a local drugs project had supported her back into education. Her worker had:

'...filled in forms to get funding, and like she knew who to get in contact with …which I wouldn't have a clue . . . and she came to college with me to try and like enrol me' (Participant 4, p348).

Other women talked about the support that their key workers had provided in terms of accompanying them to medical appointments and supporting them with practical tasks, such as budgeting. This person-centred approach was not just confined to key workers from specialist community services. Participant 5 said staff in the refuge where she lived had contacted various services on her behalf, including drug workers and social workers. Where women did not have a good rapport with their key workers, this was sometimes because the initial contact with a worker did not get off to a smooth start (Authors, p348).

2. Fragmented services

Women talked about the lack of co-ordination between services. The dispersed locations of services was an issue:

'…It's just when they pass you from pillar to post, from post to pillar . . . and that's what they're doing with me . . . the other day I had to go all the way to do an assessment, and then they wanted me to go to yesterday. That all costs money, buses and that . . . or I have to walk it. And by the time I've done all that, I'm knackered…' (Participant 3, p349)

A woman described in her second interview the issue of conflicting advice about which services she could attend:

'…if I'm going to one organisation I'd like the information and the advice I'm given to be consistent, so I don't come out even more confused than I already am' (Participant 6, p349).

Another woman said about services:

‘…they occasionally fail to pass messages on, and that’s cos they’re all over the place…’ (Participant 7, p349)

Most of the women were attending one-to-one counselling or group sessions as a requirement of the support they received, either from their housing agency or specialist support agency, and their experiences were mixed and one woman recalled that counselling had:

'Helped me with my anger like obviously … overdosing, self-harming, things from my childhood' (Participant 8, p349).

But others found these sessions 'harrowing and unhelpful', while group sessions were universally thought to be intimidating and difficult to attend (Authors, p349).

3. Statutory social work services

Several women said that they had been involved with social work services, either in their own childhood or as a parent involved with the children protection system, but did not feel comfortable talking about their experiences with services (Authors, p349).

Despite the complex nature of their needs, none of the women said they were in contact with social workers from adult services (Authors, p350).

4. Women-only services

The history of abuse and sexual violence experienced by women meant that having access to women-only services, including hostels, was a fact that was often mentioned. Mixed hostels were seen as hostile places. Participant 7 spoke of the significant part that respite at a women’s morning within a specialist drugs project played in her care:

'Because it’s just somewhere you can go and have a cup of tea and paint your nails and there’s people there . . . if you need some support they can help you sort of thing' (Participant 7, p350).

5. Changes to services

Over the duration of the research, the local authority re-commissioned some of its supported housing contracts; budgets of services were cut and the women-only night shelter closed. Women spoke of the negative impact this had, such as not being able to have the same key worker anymore:

'…They had a whole massive mix up in a load of people had to be let go and they had a budget cut … so she isn't a support worker any more, she's got a different role in which is a shame'. She said that staff were having to support more women, appeared more stressed and had less time for individual women (Participant 7, p350).

Considerations: The researchers recruited 38 instead of the 40 women they had intended. Furthermore, 16 women dropped out of the study. Some women only elaborated on their experiences of needs as they began to feel more comfortable with the researchers. As a result, the authors point out that although the research provides a description of the social care support women received and their experiences of this, it could not provide enough detail about how their needs changed over time. Overall, however, this study has been well conducted with a clear description of methodology and analysis of findings.

Goodman C, Amador S, Elmore N et al. (2013) Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes.

Methods: Exploratory, qualitative study that used guided conversations with people with dementia living in care homes, conducted as part of a four-year longitudinal mixed-methods study.

Data: Views of older people with dementia about their life in the care home, their health, thoughts for the future, and aspirations about end of life.

Country: UK.

Setting: Care homes.

Scoping framework areas: Personalised support; continuity of care and transitions; care and support for people’s needs.

This study was rated overall medium (+) quality. The aim was to explore how older people with dementia discuss their priorities and preferences for end-of-life care, and how this might inform subsequent discussions with families and practitioners.

Sample size: 18 people with dementia, living in 6 residential care home settings (that is, providing personal care only). Thirteen women and 5 men with a median age 84.7 ranging from 68.7 to 92 years. Older people who were either formally diagnosed with dementia or considered by the care home manager or staff as having symptoms indicating that dementia might be present were approached and invited to take part in the study, and agreed to be interviewed. The participants were purposively sampled - residents from each of the 6 care homes and with different care trajectories were recruited, with the key inclusion criterion being the ability to engage in a conversation. This latter criterion meant that a section of residents were automatically excluded.

Analysis: Data were systematically grouped into categories that initially kept as close as possible to the older people’s accounts of events and experiences (Tesch 1990). Categories were reviewed and combined or linked together where there was overlap or similarities. Within and between categories, links were made, negative cases noted and key themes identified (Coffey and Atkinson 1996). Two researchers reviewed and refined the themes, which were checked with the wider research team and two members of the public involvement in research group who had experience of family members living and dying in care homes.

Findings

For many residents, an awareness of their dementia affected their self-esteem and confidence about whether their views were worth listening to, and if they could influence decision-making about current and future care (Authors, p1642).

Most residents were able to talk about their thoughts and feelings about living and dying in a care home but on their own terms, usually emphasising particular issues or stories, or how they had managed illness in the past. Three themes that had relevance for thinking and talking about the end of life were identified; dementia and decision-making, everyday relationships and the significance of purpose and place.

1. Dementia and decision-making

Having dementia and living in a care home meant the older people often accepted that staff, family members and visiting clinicians would make decisions on their behalf. One man assumed his age was a factor in staff deciding not to treat any future illnesses:

'And people of my age, they don't [admit to hospital]…they just let us kick the bucket, don't they? Do you know what I mean by 'kick the bucket'?' (Participant 1, p1643)

One woman saw the dementia as a restriction on going out alone, and did not think decision making on her behalf was reasonable:

'Well I'm not allowed to [go out alone] in case I forget where I am and I don't know my way back, but, I said ‘‘can I just go and have a walk around the grounds'', ‘‘no''. I'd obviously find my way back from out in the grounds wouldn't I, I would have thought. I said that this afternoon to one of the girls ‘‘can I go and have a walk round'' she said ‘‘oh no''' (Participant 2, p1643).

Despite reluctance, older people's ability to express preferences was a consistent finding in most interviews, but not everyone was able or wished to be specific about future care.

2. Everyday relationships

Older people's views about end-of-life care were shaped by their daily experience of care and quality of relationships with care staff. For example, one woman strongly spoke about her dislike of being disturbed and the noise of other residents and what she saw as staff 'manhandling' her. This description highlighted how she wanted to be talked to. This information could have been recorded and used to provide ongoing and future care.

The quality of the relationships that people expected they would experience was a continual theme. One resident expressed it as friendliness and responsiveness, and felt sure the staff would look after her.

'It's the friendliness that keeps you going, I mean if you are not well, they're in there in a shot. . .they really (resident emphasis) look after me, they'll call the doctor, well I've had two good years this time, I've been in a while, but I've, the last two years I've got really well' (Participant 3, p1643).

The care home was a place where individuals felt supported and where they would want to stay. But many participants distinguished between the kindness of the staff and the more negative experiences of a disciplined approach to care, the loss of their homes and few opportunities for meaningful participation.

3. Significance of purpose and place

Conversation was often described in the context of loss, for example home or family, and, significantly, how these losses had an impact on their purpose in life. The effect of dementia intensified that experience but it was multi-layered.

Even when residents had come to terms with living in a care home and grateful for the support that they received from staff, thoughts about their own care needs and preferred place of care was dominated by these losses.

Considerations: The authors state that while there were recurring themes, data saturation (where no more patterns or themes are emerging from the data) may not have been reached. This could be attributed to factors such as some interviews being of short duration or covering too many topics without a proper focus. Furthermore, some interviewees found difficulty in expressing their views, which meant that answers lacked detail. The authors report that as researchers were not acquainted well enough with participants, interpretation of views was sometimes difficult for them. Other methods of communicating ideas and views about end of life could have been explored, for example, through observation, visual aids or biography and stories. However, despite the above limitations, the authors point out that careful attention was paid to what older people thought was significant about ongoing and end-of-life care. One other limitation is that the analysis does not distinguish the findings between types of care homes and characteristics of participants.

Hamilton S, Tew J, Szymczynska P et al. (2016) Power, Choice and Control: How Do Personal Budgets Affect the Experiences of People with Mental Health Problems and Their Relationships with Social Workers and Other Practitioners?

Methods: This paper draws on in-depth qualitative interviews with service users with mental health problems and with mental health practitioners, conducted in 2012 to 2013 as part of a national study exploring the implementation of personal budgets.

Data: Views and experiences of people using mental health related social care services and social work and other practitioners.

Country: UK.

Setting: Care homes.

Scoping framework areas: Respect, dignity and control; personalised support; information and communication; active participation in lived experience of care.

The aim of the study rated overall high (++) quality was to explores how, within mental health services, people's experiences with personal budgets may have affected their perceptions of empowerment and their relationships with social workers and other mental health practitioners.

Sample size: 52 service users with conditions including schizophrenia and related psychotic disorders, bipolar disorder, depression and personality disorder. Service users' age ranged from 21 to 71 with a mean age of 44. Men service users numbered 20 and woman service users numbered 32. Regarding their status in relation to receiving a personal budget: 37 service users were using a personal budget; 7 people were seeking/arranging a personal budget; and 8 had finished using a personal budget. Sampling of interviewees was undertaken in a careful and sensitive way, using a mental health professional as a conduit and allowing for potential participants to decline the invitation to participate.

Analysis: Analysis was undertaken using an Interpretive Framework Approach (Ritchie and Spencer 1994), which employs a matrix-based analytic method to classify and organise data into themes and provides a systematic and transparent overview of data at different levels of coding. Together with 10 service user researchers who formed a research advisory group, an initial framework was designed around research questions and themes coming out of the data. A sub-group systematically coded the transcripts using the framework. Both the coding and framework were reviewed again as part of the larger advisory group to ensure consistency and see if themes had changed or new themes had emerged. After consensus was established on a final framework, transcripts were coded, collated and summarised using the software NVivo9. A matrix containing summaries of each coded quote ensured there was transparency in the portrayal of agreements and differences within data.

Findings

A number of themes connected to experiences of power, choice and control in the process of accessing, arranging and using a personal budget emerged.

1. Attitudes and values

A key difference was whether a personal budget was seen as a right or as a privilege (Authors, p726).

Where service users were unclear about the reasons for getting the budget, they could feel disempowered, while on the other hand, clarity helped engender a better sense of entitlement.

'…it feels less like you're going begging if you know where you stand.' (Participant, p727)

Where the personal budget holder did experience real control, this could add feelings of burden and pressure:

'When it comes to the use of public money for your care, which is what we're talking about . . . I just think you have a bigger responsibility with it, as well as a freedom.' (Participant, p726)

However, most service users expressed how grateful they were for receiving a personal budget, and therefore thought that they could or should not negotiate the amount received:

'I was just so grateful to get it really that it didn't cross my mind to negotiate for anything' (Participant, p726).

2. Perceptions of capacity impact on the process and decision-making

In local authorities where eligibility criteria are restricted only to individuals in highest (critical) need, some participants were offered personal budgets at a point when they were still very poorly or did not feel able to manage or monitor the budget without support:

'I was against it, as well, because they said 'you will get paid and you've got to set up a bank account', and I thought, with not being well, why is all that?' (Participant, p727)

'If I was on my own at home, and in control of it myself, I don't know what I'd do with it, to be honest . . . I have to have somebody control that side of me' (Participant , p727).

Where service users had no support, for example from a peer brokerage organisation, they relied on family and friends. The authors state that it could be paradoxical that individuals were given the potential for choice and control through a personal budget, when in reality it was hard for them to fully get involved in the process, but that with time the benefits could be appreciated, as described below:

‘To be honest, I didn’t want no control to start with when I first applied. I found it easier just to let them deal with it, but this time round they’ve given me the budget and I just pay it as I go’ (Participant, p727).

Where individuals perceived that they lacked capacity, this could be intensified by overly bureaucratic local authority systems.

‘…the problem was that it was really hard to do. I think you have to have a PhD to understand it.’ (Participant, p727)

3. Power relations and orientations

i. Control as a transfer of responsibilities

Several budget holders talked about the pro-active part they had played to secure their budget, for example, through doing self-assessments and writing support plans and letters to key contacts, which in turn provided them a sense of control and power.

ii. Resistance to transfer of responsibilities

Other service users were resistant and would rather let others manage the responsibility of a personal budget on their behalf, reflecting what the authors call a ‘learned passivity’ (Authors, p729).

‘I wasn’t really participating . . . because it’s sort of the [mental health practitioner]’s job to do things like that . . . I had all the control that I wanted, which was none at all.’ (Participant, p729)

Several service users said that they were not aware that they were even permitted to be involved in the process:

‘My opinion isn’t even asked for . . . I was sat, quiet, she was filling in the forms, and then she said “sign it”, and I didn’t get a chance to read it.’ (Participant, p729)

iii. Choice as a shared and supported activity

Although some service users described feeling very independent in making decisions and taking control of their support, most described that choices were made through discussions and reflection involving others. Both service users and practitioners highlighted that making choices together was much easier when there was a sense of rapport between them and a sense of mutual trust had developed.

When working with practitioners to secure their chosen use of a personal budget, some service users described having to be:

‘…so assertive and very confident’ (Participant, p730).

‘It was almost like I felt pressured to go with what she wanted because I don’t want my care to be affected with her if I don’t answer the way she wants me to’ (Participant, p730).

4. Local authority approval

Most interviewees described the decision-making process with practitioners in relatively positive terms. This compared with a lack of direct communication and knowledge about local authority decision-makers and a ‘perceived obscurity’ of how decisions were made and signed off:

‘All communications [were] between my support worker and somebody, I don’t know who. So very little was to do with me’ (Participant, p731).

While many service users were able, to some extent, to negotiate with practitioners, they did not have this facility at the panel meeting of managers where decisions about funding of personal budgets were often made in local authorities:

‘There’s not a lot you can do about it, is there, if someone tells you the money isn’t there then that’s the deal’ (Participant, p731).

Considerations: The findings may not be generalisable for two reasons: first, the three local authority sites may not be representative of other areas in the UK. Second, with local authorities experiencing rapid cuts in funding, policies and procedures concerning implementation of personal budgets are constantly changing, therefore approaches to practice have had little chance to become established. The authors report that the findings presented are ‘only a snapshot of experiences at a particular point in time’ (Authors, p732).

Hatton C and Waters J (2011) The National Personal Budget Survey: June 2011.

Methods: Survey but direct user views included.

Data: Views of personal budgets.

Country: England, UK.

Setting: Own home.

Scoping framework areas: Respect, dignity and control; information and communication.

This report presents analysis of data from an overall low (−) quality survey study. The study aimed to capture experiences of using personal budgets from personal budget holders and for carers of personal budget holders.

Sample size: In total, 1,114 personal budget holders completed the POET survey, including 832 returns from the 10 local authority demonstrator sites and returns from at least 76 other local authorities. Four hundred and seventeen of these personal budget holders also wrote in a comment about their experience of personal budgets – this is what is summarised in the findings section below.

Analysis: The survey responses were recorded numerically within Limesurvey, then analysed using a specialist statistical software package (SPSS). All between-group differences and associations were conducted using the appropriate non-parametric test; due to the number of comparisons statistical significance level was set at $p<0.01$ (that is, the odds of the result occurring by chance were less than 1 in 100).

For the open questions asking if people wanted to write in anything about their experiences of personal budgets (summarised below), themes were developed to summarise people’s experiences from what they had written. Each quote was then examined and assigned to one or more themes, depending on what the person had written. For most comments, a judgement was also made on whether the comment was mainly positive, negative or neutral in relation to the theme. This was done separately for personal budget holders and for carers.

Findings

One hundred and sixty-three personal budget holders commented on the impact of their personal budget on a specific aspect of their day-to-day life. The following are direct quotes from direct users – from those who added additional comments to the survey.

‘Having the personal budget has completely changed my life and of those around me. My husband who is 75 years was finding things increasingly difficult to support me, and my daughter who was recovering from breast cancer was worried about the way things were breaking down and was unable to help. I rang social services one day in tears to see if I there was a possibility of any help and within a few days I saw a social worker who told me about the budget and how he thought it would work for me. I have never looked back and the stress and worry has been taken from us. I have lovely carers who support us in every way. They help with personal care, help in the home, shopping take me to my voluntary work and meetings which I would have to give up without them as my husband couldn’t take me and we have trips out which stops me from being confined to 4 walls. My life is happier and more fulfilling now and I don’t know what would happen if the support was withdrawn. I have independence now and hopefully can help others along the way’ (Budget user, p25).

Although the account above was positive, the authors contend that most of the comments were in fact negative, as exemplified by the following narrative:

‘[The] Adult learning disability team took 14 months to process a claim for direct payments. I then was told at the time I would not have to pay a contribution. Four months late I was then told I had to pay half my carers allowance towards my care. I had also to back pay my contribution using up all my savings. It has been a disgrace. I am still unsure how to spend it, or on what except my carer. The whole process has taken 2 years and been so stressful’ (Budget user, p25).

The authors comment that relationships with staff and the ‘system’ were also mainly negative. For example:

‘Social services staff come from a different planet and have great difficulty speaking understandable sensible plain English and being answerable to their clients’ (Budget user, p25).

The authors report that respondents commented on the process of setting up personal budgets as cumbersome. For example:

‘It was very difficult to set up originally. I need to use contingency fund but have no idea how? Once set up there is no info on how to change/alter/reassess it. Once set up you are discharged from social services and have no idea/back up to contact on who to contact. Money is held by [broker] who don’t know much about it!!’ (Budget user, p20)

The authors also report themes captured from personal budget users in table 2, page 24. The table records that 89 participants reported positive views of 'personalised care'.

Considerations: The research design is not clearly specified and the actual questions asked in the survey are not included. Reliability and validity are not reported for the survey tool. The sampling strategy is not reported. Not entirely clear how study participants were recruited – except through local authorities. Not clear how representative the survey is of the population of personal budget holders. Subject of survey are adults using social care who have personal budgets. This is a sub-group of all adults using adult social care services and not all adults using social services will have personal budgets. Therefore, the findings cannot be generalised to all adults using social services. Survey reports only findings for people who responded; there are no details given of non-responders. Views data reported only for some participants and no details given about age, gender and other key demographics of participants.

Hillcoat-Nallétamby S (2014) The meaning of "independence" for older people in different residential settings.

Methods: In-depth interviews with older people in residential settings.

Data: Views of independence and living in residential settings.

Country: Wales, UK.

Setting: Extra-care housing, residential care settings.

Scoping framework areas: Respect, dignity and control; active participation in lived experience; care and support for people's needs.

This report presents analysis of data from an overall medium (+) quality study. The study aimed to address the knowledge gap in research about older people's own understandings of independence to further develop an interpretative framework of this concept within the context of three different residential settings.

Sample size: Population of 91 frail older people – 29 in extra-care housing, 29 in residential care homes, and 33 in the community.

Analysis: Thematic analysis techniques were employed to identify patterns in meanings of independence across settings and then interpreted using Collopy's conceptualisations of autonomy, as well as notions of space and interdependencies.

Findings

Findings show that older people's understandings of independence are diverse, with some understandings common to all three settings, others specific to a setting. The following two themes have been selected, as they highlight the views and experiences of participants in relation to their use of social care.

1. Older people's understandings of independence

Independence is manifested in a willingness to purposely accept help at hand. One resident explains that this helps them to be more selective in deciding what they need to do to remain independent:

'The arrangements are better for me, like take shopping. I can do it independently… the energy that I used to waste with trying to shop and cook, it's taken from me now, I don't have to do that, I only have to think about breakfast or tea and that's easy' (Extra-care housing service user, age 79, p5).

Access to personal financial resources to pay for help promotes a sense of independence by giving respondents more choice and control in how they organise their lives. Despite increasing frailty, an extra-care respondent continues to see herself as independent, her ability to organise and pay for much of her own care needs illustrate this:

‘I have got in touch with the All Care Domestic Services myself. Nursing services they are. I have privately got a helper who comes on a Thursday and she does my shopping at the Co-Op …, so I’m still independent’ (Extra-care housing service user, age 83, p6).

One respondent living in the community says that despite some financial help for ironing, they are able to take on the costs of other care themselves:

‘I get home care. My ironing’s paid for by Supporting People services and my other ordinary care I pay for me self. That is personal care to get me washed and dressed in the morning – it all helps me’ (Service user living in the community, age 65, p6).

2. Cross-settings

The authors’ comment that 'Having access to and using resources to receive services at home promotes a sense of independence’, for example one respondent says:

'If you need help with your housework we get domestic time as well so that everything is looked at and seen to […]. So the domestic time is included in the monthly payments and some might need a lot more than others and then you find somebody who is more independent’ (Extra-care housing service user, age 78, p6).

The authors argue that respondents’ independence was evident in terms of them openly asserting independence, as one resident comments:

‘I basically look after me self. I can do everything myself. I’m not like some of the people here; I am capable of looking after myself’ (Residential care service user, age 75, p6).

Similarly in the community, a respondent who is asked to explain why they have opted to receive help at home affirms:

'(…) you see, dependency in my view becomes more and more inevitable to the extent that you allow other people to do things for you. You have somehow to be as independent of gratuitous outside help as you can possibly manage because if you don't use it you lose it' (Service user in the community age 76, p6).

In the residential setting, a respondent says that, if given the opportunity, she could do more for herself:

'Interviewer: So, you don't have the option of getting yourself washed and dressed?

Respondent: Oh no, no.

Interviewer: Do you think you could?

Respondent: I'd have to have help, I think, especially to get dressed but I think I could wash myself, the way they do ..., you know, I'd do it in bed. I'd like to be more independent. […] in the morning, if they gave me the water and thing and you know, I'd try and have a go anyway' (Residential care service user, age 86, p6).

One respondent points out that having moved to extra-care because of her husband's deteriorating health and wellbeing since arriving there, she is free to continue her own activities and to go out because she can rely on support staff:

'No we've got a better quality of life since we've been in here. I know now I can go out and I know there's help on hand if anything happens to him. Because I mean like a few weeks ago I wasn't here and he had a heart attack. Well all the staff was here, you know … ' (Woman, age 62, p7).

Respondents spoke about how having a care plan in place assisted their transition from hospital:

'Last year I fell upstairs. And then they took me into hospital, sent me home and from there I've had the care plan that I have now… I got a stair lift and now I manage' (Woman, age 86, p8).

Considerations: The focus of this study was the meaning of independence for older people in different settings, so this does not entirely match question 1 for this review. No reference is made in the study to ethical issues. The authors conclude that the results need to be interpreted in light of some limitations: 'The study is based on a relatively small convenience sample from Wales, and for financial reasons, qualitative data collection was only completed for half of the original total sample, thus compromising the ability to generalise from the findings; some findings are likely to be context specific, for example, physical adaptations would normally only be introduced to the private dwelling, as both extra-care and residential settings are likely to incorporate these design features' (Authors, p10).

Irvine F, Yeung EYW, Partridge M et al. (2016) The impact of personalisation on people from Chinese backgrounds: qualitative accounts of social care experience.

Methods: In-depth semi-structured interviews.

Data: Views of social care experiences of physically disabled people from Chinese backgrounds.

Country: England, UK.

Setting: Community care services, own home.

Scoping framework areas: Personalised support; information and communication.

This report presents analysis of data from an overall medium (+) quality qualitative study. The study aimed to examine the factors affecting the social care experiences of physically disabled people from Chinese backgrounds in England. In-depth semi-structured interviews were carried out in the language of choice of the participants (English, Cantonese or Mandarin) between July 2012 and February 2013.

Sample size: Purposive sampling was used to recruit people from a Chinese background with a physical impairment who had received social care from adult services in the previous 6 months. This included snowballing techniques – individuals who agreed to take part in the study were asked to pass on recruitment flyers to potential participants. The research team invited all who took part in an interview to attend the focus groups; no second stage sampling or filtering was conducted. Twenty-six people were interviewed.

Analysis: The interviews and focus groups were audio recorded, fully transcribed and anonymised. Transcripts were analysed in the original language of the interview, and bilingual labelling was used through the analysis to accurately describe participants' experiences and retain any linguistic nuances. The interview transcripts were searched for patterns in the data and coded into sub-themes before agreeing on a preliminary thematic framework. Themes were scrutinised by an independent researcher by cross-checking to ensure correspondence, and systematically tracing interview quotations. Focus group data were analysed separately following the same analytical process as for the interviews. Comparisons were made between the two data sets to elicit new meanings and insights and to enhance the trustworthiness of the findings.

Findings

Information and communication:

The narrative accounts focus on knowledge and information received on personal budgets. Most did not refer to personal budgets and when questioned directly about them, claimed that they had little knowledge, for example:

'(I've) never heard of personal budgets' (Female participant, 69/F, p5) or 'No one ever mentioned personal budgets to me, the Chinese community worker never told me about this' (Male participant 50/M, p5).

The authors comment that a small number of participants were aware of personal budgets, but that participant accessibility to them was constrained because of difficulties navigating 'what was viewed as an overly complicated system' (Authors, p5). For example, one participant said:

'I used personal budgets for a while, but it was too troublesome. Even my daughter was put off by it, although she can speak English. Nothing is perfect, we had to employ someone, and it took time to do it, organise the payroll, pay slips, their leave

. . . There is a lot to learn. In the end, my daughter and I agreed not to use personal budgets' (Female participant, 34, p5).

And another said:

'It sounds very troublesome. I don't know many people. If I have to employ someone, I don't know where to find this person' (Male participant, 68, p5).

The authors report that many participants were unable to utilise the resources provided by personal budgets or were not sure if they were even entitled to access them. The authors go on to comment that this lack of knowledge and information led participants to ask family and friends to meet their social care needs:

'You know I had three operations. I cannot put the socks on myself. Sometimes I feel really miserable. I need to ask my husband to help me take my shoes off. It is very stressful for him. He is getting old and he needs help as well I am not sure if I am entitled to personal budget, direct payment' (Female participant, 36, p5).

The authors report that the desire to maintain individuality meant participants avoided using available services because of issues of trust or pride. For example, one participant said:

'If the government gave me money to hire someone to look after me, I will only hire my daughter … I had negative experiences with care workers in the past …I will only trust my daughter to look after me' (Female participant, 69, p5).

Personalised support:

Cultural values and linguistic cultural values had pragmatic implications on the way social care services were received. For example, the authors cite the following example of the importance of food within Chinese culture:

'We Chinese, you know what I eat is simple Chinese meals. Unless you can employ a westerner who can prepare Chinese food but that is impossible' (Male participant, 50, p5). And another said: 'You know when you cannot speak the language, you cannot communicate with others. It's very troublesome... even if the social worker comes to see us, it’s no good if we cannot communicate with them’ (Female participant, 50, p5).

However, the authors report how personal budgets can be used to help mitigate such problems so that 'services aligned with their cultural needs and preferences' (Authors, p6).

‘Personal budgets allow me to hire Chinese-speaking domiciliary care... it helps me to get someone with the cooking, cleaning, shopping. Without the budget, I will not be able to do anything I received the service as I expected and I am happy with it’ (Female participant, 35, p6).

The authors argue that their study shows that:

‘When people from Chinese backgrounds make use of personal budgets, they are able to exercise choice and access much needed culturally equivalent services that may not be available through conventional means’ (Authors, p6).

The authors argue this conclusion is in line with previous findings on other marginalised groups.

Considerations: Although it is clear the respondents were those with a physical impairment who had used social services in the previous 6 months, it is not clear where the participants were receiving the care. It seems likely all were home care based (own home) or in the community but this is not confirmed in the paper. There are a number of notable limitations reported by the Authors on page 8:

1) 24/26 respondents resided in major English cities and were mainly recruited through Chinese welfare organisations. This may have influenced their experiences and their levels of satisfaction such that they would not be transferable to people living in suburban or rural locations. While the authors say they attempted to portray a balanced report of participants’ experiences, they agree it is possible that their accounts were coloured by their perceptions of the interviewing researchers and the perceived balance of power between researcher and researched.

2) The Authors say that the professional social worker status of the ‘insider’ may have influenced or inhibited participants’ disclosure of their experiences.

Katz J, Holland C, Peace S et al. (2011) A Better Life: What older people with high support needs value.

Methods: Conversations with older (and some younger) people with high support needs using semi-structured interview schedule. Conversations also held with volunteers and professionals working with people with high support needs in a range of organisations.

Data: Views of what older people with high support needs value in their lives, and within services.

Country: Scotland, Wales and England.

Setting: Range of settings including own home and care homes.

Scoping framework areas: Respect, dignity and control; personalised support; information and communication; active participation in lived experience of care; care and support for people's needs.

This report presents analysis of data from an overall medium (+) quality study.

This study is part of Joseph Rowntree Foundation's 'A Better Life' (2009 to 2013) programme. The primary aim of this project was to produce a robust framework highlighting what older people with high support needs want and value. The purpose of the framework was to:

- inform the work of the whole 'A Better Life' programme
- raise awareness among policy makers, practitioners, regulators, researchers, and older people and their carers
- provide a foundation for future project work (page 9).

The framework was developed through a two-phase approach: firstly, an evidence review of the views of older (and some younger) people with high support needs about what they value and aspire to, in order to develop the overarching themes for an evidence framework; secondly, conversations with people with high support needs about what they want and value in order to endorse the framework.

Sample size: 26 people using services, of whom 10 were men and 16 were women and ages ranged from 40 to 93. Four black and minority ethnic people were included. Most people had mobility and/or sensory impairments and at least one additional serious health condition; 9 were diagnosed with dementia; 2 people had learning difficulties; and two people had been born with severe physical disabilities.

Twenty-one people were in receipt of formal care and many also received care from relatives or friends. Some people lived in care homes or supported accommodation; over half lived in their own homes in the community; and two were homeless people.

Analysis: The transcribed conversations were analysed against the categories in the evidence framework. New categories were added as these emerged and then verified by team members (Authors, p19). In their analysis, the researchers grouped themes or sub-themes according to how often they were mentioned and the importance given to them by participants (p20). Analysis also involved comparing the evidence framework with frameworks produced in other similar studies.

Findings

The output of stage 1 consisting of the evidence review of what older participants or those with high support needs have said they value was an evidence framework, which consisted of social, psychological and physical factors and things that act as barriers or facilitators, for example information and support. Stage 2 conversations with study participants about what they valued tested out this evidence framework. Generally, the participants agreed on the significance of the themes developed in the framework and were able to support these with their own examples or add new themes. Below are the ones specific to the guideline.

1. Good relationships with carers

Paid care workers offer older people with high support needs regular social contact and can reduce isolation.

'I'm going to need help in the mornings, and I'm glad of the help really, because I wouldn't see a soul otherwise, and I'm woken up and they are wonderful really' (Female participant, 85, living alone in her own home, p24).

One of P's carers is the link between P and another person she supports, having recognised that the two have common interests. Pnow enjoys sending and receiving cards and messages through the carer to the other person, who is blind.

This example shows that good relationships with carers are not just about receiving good care, but are an end in themselves in that they can help promote positive social connections and friendships (Authors, p24).

2. Psychological wellbeing; self-determination

Within this theme, the Authors discuss the concepts of independence, autonomy, involvement in decision-making and control. For many of the participants, staying in control of key aspects of their lives was fundamental to their self-esteem. Furthermore, from a practical viewpoint, this was absolutely essential for health and safety reasons as described in the case of one female participant, who has dual sensory impairment. She wanted the opportunity to show each new carer around her kitchen and familiarise them with her system.

'Being partially blind I have to know where everything is and I have my big plates there … my saucers there … she put the saucers on top of the big plates, course I went in there … whole lots went crash on the floor … now when they come I say to them … don't put anything on top of those big plates' (Female participant, 85, who has dual sensory impairment, p27).

Where people were living in institutions and no longer had control over the day-to-day running of the household, some had simple requests for things to be made available to them. One woman wished that the nursing home staff would keep the food residents asked for in the kitchen: she particularly wanted fresh ham (Authors, p27).

3. Barriers and enablers

The authors describe cross-cutting themes such as: information; financial resources; support; other people's time; transport and equipment; and technology and communication. People talked about these resources as the means to achieve the things they valued and which helped promote their social, psychological or physical wellbeing. A lack of these resources was seen to create barriers to achieving the things that mattered to them.

i. Information

Access to information was a random affair and mostly provided by health and social care professionals and family members. Information was generally sub-standard in quality and consistency and had implications on access to care. People with visual impairments were often dependent on others to read letters and documents to them.

A male participant (40), who has a learning disability, is registered blind and has mobility difficulties, had missed out on a care package for 15 years because neither she nor her family had been given information that about her eligibility.

A female participant had not been aware of extra care housing until a social worker's visit coincided with a visit from her son.

'The social services lady happen to come to see me when my son was visiting and she said, "well have you thought of going into sheltered accommodation," I said "no, they wouldn't let me do that", she said "they would … you're so independent, you're not safe," she said "have you had a leaflet about [place]" – she said "If I were you, I'd go and look at it." I didn't know anything about them, no … I didn't know I could move into a place like this and it would just be like my own home…' (Female participant, 89, who has dual sensory impairment and uses a wheelchair, p36).

ii. Support

Where people need significant amounts of support, the quality of the care they receive and the relationships they have with carers are of particular importance in their own right. The Authors reiterate that carers are the main source of social interaction for some people. However, timely and effective support are also a means to an end, and can enable older people with high support needs to get out and about, and to participate in social activities.

'If I really wanted to go somewhere and I asked if they could sort it out, the staff, they would sort it out' (Male participant, aged 50, with tetraplegia, p37).

On the other hand, where support is erratic, inflexible, not responsive or provided at the wrong time, it can create barriers by preventing people from doing things that are important to them.

'Sometimes she's not here till about 10.00, maybe sometimes after 10.00 … she's got so many others to do, they need more done than what I do so I just have to accept it … I'd rather it was a bit earlier, but there's nothing that can be done about it, so I just have to get on with it and accept it and that's it' (Female participant, 85, with mobility problems, p37).

iii. Other people's time

Many people talked about the importance of carers having enough time to spend with them, not only to provide practical support, but also to listen to how they want tasks to be done. This was especially so for those with severe communication difficulties (Authors, p38).

iv. Transport and mobility

Where people had suitable mobility equipment or accessible transport in place, this clearly had an enormously positive impact on their quality of life:

'Tell you what's been a wonderful thing to me, has made a difference in my life, that wheelchair, it's given me a lease of life … [had it] five months … oh it's made a difference to my life' (Female participant, 89, with dual sensory impairment and severe osteoporosis, p38).

v. Technology and communication

For those people with hearing impairments, a lack of the right technology hindered communication. Two participants' problems with their hearing aids severely restricted their use of the phone and their ability to hear when in a group. For another participant, lack of a loop system meant she had to have the television on so loud that she disturbed the neighbours.

'You see I have to have it on louder than I thought it was, cause I would hate to upset the neighbours … I have to explain that I'm deaf and blind... so hopefully [her support worker] is going to get me a loop system cause it's the only information I get on the news here …' (Female participant, 89, with dual sensory impairment, p39).

Considerations: The findings were based on a small sample of people and therefore may not be representative. The researchers acknowledged the limitations of gathering certain types of factual information from people with cognitive impairments, but nevertheless felt confident that the information collected was reliable and the 'conversations provided some verification by older people with high support needs of the recurring themes from other studies' (Authors, p19).

Rainbow Ripples and Butler R (2006) The Rainbow Ripples report: lesbian, gay and bisexual disabled people's experiences of service provision in Leeds.

Methods: In-depth interviews with service users, key service providers, and a questionnaire survey of a broad range of service providers.

Data: Views of service provision among LGB Disabled People.

Country: England, UK.

Setting: Community care services.

Scoping framework areas: Respect, dignity and control; personalised support; information and communication; care and support for people's needs.

This report presents analysis of data from an overall high (++) quality study. The research aims to explore the way services are provided to LGB Disabled People in Leeds. By LGB Rainbow Ripples mean anyone who is lesbian, gay or bisexual or is questioning their sexuality. By Disabled they mean anyone who finds themselves discriminated against in society because of mental distress, physical or sensory impairment or learning difficulty or because they are a Deaf person.

The research objectives are to: a) gain an understanding of the needs and aspirations of lesbian, gay and bisexual disabled people in Leeds, b) assess current service provision from statutory, and voluntary agencies, and private businesses for lesbian, gay and bisexual disabled people in Leeds, c) gain an understanding of what constitutes good practice, d) inform service providers of lesbian, gay and bisexual disabled people's needs and how they can best meet them, e) create training materials on the issues raised for courses on health and social care, f) communicate the results of the research widely with all interested parties, and g) raise the profile of lesbian, gay and bisexual disabled people and the barriers they experience (Authors, p21).

Sample size: 20 service user participants.

Analysis: The questionnaire data was coded and entered into a specialist statistical analysis software package (SPSS). Established quantitative analysis techniques were used to produce the statistics, involving the calculation of simple descriptive statistics, cross tabulations and relevant graphs.

A practice of data coding based on that described by Cook and Crang (1995, 80–92) was adopted for the interviews with lesbian, gay and bisexual disabled people and service providers. These interviews were tape recorded and lasted between 50 minutes and 2.5 hours. The lesbian, gay and bisexual disabled interviewees were then also given the opportunity to check their transcripts and amend or add to them, as they felt fit. The transcripts were then read and reread and the issues and themes they raised coded. Coding sheets, listing all the codes marked, were reflected upon, and commonalities and differences between interviewees noted. Finally the results of this analysis were reflected upon in relation to past research on lesbian, gay and bisexual disabled people's experiences (discussed above), and current service provision practices and policies.

Findings

Page 7: The authors summarise the unique experiences of lesbian, gay and bisexual disabled people as follows:

'There are few services which specifically consider LGB disabled people. There are problems of homophobia in services particularly aimed at/developed for disabled people. There are problems of disablism in services particularly aimed at/developed for LGB people. There are interrelated misconceptions about disabled and LGB people which impact on service provision. LGB disabled people sometimes have to deal with homophobia and disablism at the same time. The combination of the two can make their overall experience more than twice as bad as either experience on its own. LGB disabled people have their own culture and have sometimes responded creatively to the discrimination they face and gained personal strength, confidence and determination from their experiences' (Authors, p7).

Views and experiences of lesbian, gay and bisexual disabled people are discussed in the following areas: technical aids and equipment; personal assistance; and advocacy.

1. Technical and equipment

Page 127: Access to information on the availability of equipment was reported as a barrier to having what may be useful pieces of equipment. As one interviewee put it:

‘There’s a whole host of probably technical aids and equipment I could do with, but I don’t know that they exist. And I probably haven’t found them out. So like for undoing bottles, for taking things off...' (Service user participant, p127)

Page 130: The Authors discuss that disabled people are usually reliant upon the expertise and advice of GPs, care home staff or other health and social care professionals, who hold power in controlling information and distributing technical aids and equipment. However, people mainly come into contact with such services at the onset of their impairment and not before.

Page 131: The Authors report that:

‘While self-referral is becoming more common, the need for medical assessment and health professional referral for technical aids highlights how powerful health professionals are in disabled people’s lives. Many disabled people have no ‘health’ needs, implying that other routes should be available to access potentially helpful specialist equipment’ (Authors, p132).

The Authors comment that everyday items (for example, video recorders) can substitute for technical aids for some people, but other items may only be accessible through a small number of specialist suppliers. One interviewee recalled the homophobic behaviour of staff at the Leeds Centre for Deaf and Blind People:

‘I remember asking them, the equipment officer, saying “What happens, if my alarm clocks broken, what do I do?” You know, do I have to go and buy a new one, or do you replace it, or what happens. So, they knew I was gay, so they said, they just said “Get, get a man to come and wake you up. That’ll be alright.”... I mean I was, you know, obviously annoyed about that... Then I went through the interpreter... at the local communications support unit, so I went and said “Look I need this alarm clock now.” You know, “Ring the equipment officer.” You know, I explained. So the interpreter rang the equipment officer and said “Look we need an alarm clock now.” And then the message came back via the interpreter saying “Oh don’t worry about it, you can sleep with the interpreter and they can wake you up in the morning.” So of course the interpreter is really put out by this’ (Service user participant, p131).

Page 134: The Authors discuss that limited funds from a small pool of suppliers mean that the range of equipment and training in how to use it is often poor, as this service user said:

'Well I went, I did a Social Services assessment. Not long after I came to Leeds and I went yattering on then about doing computing...And they just wouldn’t have it at all. They just won’t allow Blind people, to err, to have computing equipment through their Social Services assessment. […] They don’t see it as a priority. Well I’m sorry, but communication is. As a political point it is a priority for blind people’ (Service user participant, p135).

Page 136: The Authors comment that technical aids and equipment have often been designed by non-disabled people with little input from disabled people. Service providers distribute unwanted and unhelpful equipment to disabled people, while direct requests for equipment by disabled people are rejected. One man who was born without one hand explains:

‘I mean I had another artificial one [hand] which was a hook which worked on, it was a hook that was split […] into two that I could pick things up with and it was used by, there was a pulley system fastened to my right shoulder round to my left hand, so when I extended my left arm, these hooks would come open, and apart from looking like a bond villain, they weren’t a great deal of use. […] And I had different hooks, I had a big hook, a small hook and a straight version and I had a fork that was a knife on one side, a fork on the other, so (laughter) and you know the irony being, I don't use any of them really but they were the best they had for me' (Service user participant, p136).

2. Personal assistants

Page 140: 5/20 lesbian, gay and bisexual disabled interviewees indicated that they were receiving paid support from a personal assistant. However, some service users expressed problems with this arrangement, for example this person commented on the homophobia and racism she had had to endure from a personal assistant:

'At the moment I'm not getting out of the house at all because I'm not using the Independent Living Fund. I haven't re-employed anyone after a pretty disastrous experience with someone that just didn't suit at all. She was racist, she was homophobic, you name it' (Service user participant, p142).

Another participant said:

'There's also issues when I have had boyfriends there [at home]. Carers kind of. They're not very good at dealing with that whole situation really' (Service user participant, p148).

Personal assistance in the home with domestic and personal tasks was the most common support cited by interviewees. The Authors comment that the assistance people felt they needed outside the home was often thought to go unrecognised by service providers. One man explained about the staff in the residential home in which he lived:

'What I get is pretty inflexible as to timing for a start. Also, errm, they claim that they're working towards independent living, but they don't provide the support that people need to go out and do things. They only provide personal support. I don't know what you might call nursing care or whatever really, even though they're not a nursing home' (Service user participant, p142).

The Authors say in response to this quote that:

'This highlights a common frustration with the limited range of activities which professional, paid, personal assistants would perform. For LGB disabled people, the ability to use personal assistance outside the home may be vital in terms of contact with the LGB community. LGB community activities tend to be organised on a citywide rather than a neighbourhood basis. Thus, a lack of willingness to provide these types of assistance may lead to a higher level of social isolation for LGB disabled people than for other disabled people, who may be able to access friendship networks more easily, through for example the local pub or activities specifically for disabled people' (Authors, p143).

The study reports that assessments for personal assistance and other needs did not take place regularly, therefore services could become outdated as people's need changed. Participants commented on the desire for flexibility:

'I need someone to be flexible. It depends what time I get my morphine. If I need to be out by 10am for a meeting I need it early, but they won't do an occasional early start' (Service user participant, p145).

In terms of direct payments, the Authors comment that one participant described the low staff awareness of direct payments:

'I had a social worker who didn't know anything about direct payments. I told her what she needed to know. She hadn't had any appropriate training on it. And even though they say that they do these days, a lot of people that I know who have gone on to direct payments, the social workers do not understand it at all. Errm. And it just takes an incredibly long time to get it sorted out' (Service user participant, p146).

3. Advocacy

The Authors report that there was little awareness of the nature of advocacy services with people often turning to family and friends for advice and support.

One man described this in terms of the lack of control he had:

'Oh yes I have, and it's not been forthcoming. Particularly in the residential home that I've lived in, and particularly to do with sexuality issues on one particular occasion. Err, management have got a tendency to kind of gang up. The, the, they come in the meeting too strong, because I'm apparently, I'm this stroppy disabled person and, and they're scared of me in a way. They don't seem to realise that I also need support sometimes' (Service user participant, p153).

The Authors comment that advocates sometimes did not listen or made assumptions about the lesbian, gay and bisexual disabled person, for example:

'They didn't listen to me. They talked like I weren't there. You know. They just talked to each other' (Service user participant, p153).

And another said:

'It just annoys me. They decide what's best for you, what you want. They assume I want to go to gay bars and stuff and I'm not into it' (Service user participant, p153).

Considerations: The sample selection and analysis was not theoretically grounded. The Authors report that: 'Interviewees ranged from people with little obvious control in their lives, who were using segregated services - such as day or residential care, or were dependent on relatives for personal support - to LGB disabled people who had attributes associated with independence and control - such as being home owners. LGB disabled people in these situations may feel more confident in coming forward for interview, so this may not be a representative sample' (Authors, p46).

Swain J (2005) Independent Evaluation: Developing User Involvement in Leonard Cheshire. Final Report.

Methods: Independent evaluation by a research team from Northumbria University, which involved two stages. Reported here is the narratives from stage 1 (views and experiences of service users and providers through focus groups and semi-structured interviews); and user views from the case studies conducted during stage 2 of the evaluation.

Data: Views of service users in relation to services provided at Leonard Cheshire organisation.

Country: Scotland, Wales and England.

Setting: Leonard Cheshire organisation.

Scoping framework areas: Respect, dignity and control; personalised support; information and communication; active participation in lived experience of care; continuity of care and transitions; care and support for people's needs.

This report presents analysis of data from an overall low (−) quality evaluation with the aim of conducting a review of and supporting the development of service user involvement at all levels and within all areas of Leonard Cheshire activity. Leonard Cheshire provides social care services including care-at-home, residential homes and the employability scheme.

Despite this evaluation being about user involvement, much of the views material addresses the quality of social care provision within Leonard Cheshire. Therefore, relevant views material has been extracted from both stage 1 and stage 2 of this evaluation.

Stage 1 views material was gathered through focus groups and semi-structured interviews. Key questions were developed with the participants around topics of: user involvement within the organisation; impact on the lives of service users; and the effectiveness of key strategies within the organisation – including training, mentoring, information, and support to users in learning difficulties services. User involvement topics included: governance; central committees; regional involvement; local services; and staff and volunteer recruitment. Stage 2 is from the five case studies, case study two and case study three provide views material.

Sample size: In all there were a total of 96 service users in the sample. Group interviews and focus groups numbered 10, where each group was made up of approximately 6 service users. Eleven individual interviews were carried out; the SURE meeting (not explained by author) consisted of approximately 25 participants. No details were provided on sample age or gender. Individual interviews, group interviews and focus groups were conducted in residential homes, day services and care in community services.

Analysis: The authors have not provided any detail on how the data collected via interviews, focus groups and case studies were analysed. It is therefore not possible to make a definitive conclusion about the validity and reliability of the findings.

Findings

Key findings:

Leonard Cheshire provides social care services including care-at-home, residential homes and the employability scheme. This evaluation is focused on service user involvement within Leonard Cheshire, rather than the quality of service provision. The authors point out, however, that it is evident 'from the views expressed by service users that such a distinction is incompatible with their experiences. The better the quality of services they receive the more, from their viewpoint, opportunities and possibilities there are for service user involvement’ (Authors, p40).

The key themes, expressed by service users from both stage 1 and stage 2 of the evaluation, are described below:

Stage 1 - Views of service users

1. Lack of 'ground level' staff

Most of the residents who were interviewed spoke about the fundamental problem of lack of ‘ground level’ staff and the impact on making choices in their daily lives right down to the most basic of needs:

'We have one bath a week, that’s on a specific day' (Interviewee, p16).

'The toilet. That to me is basic. I was desperate and I rang the bell and at last they came. There are bells everywhere but the only time you don’t have to wait is in the night. I just dread it every day...!' (Interviewee, p16)

The link between user control and the level of support was evident in the following quotes:

'I don’t feel all the time that I’m fully in control of what I do and don’t do. For instance, I can’t prepare myself a meal and I can’t move my chair without the assistance of a carer. If I want to go anywhere quickly, go to the toilet or something like that, and don’t get there in time, they say ‘You should have asked’ but if there’s not enough staff about it’s literally impossible to get there, you have to wait for someone to take you' (Interviewee, p16).

'The other night for what I wanted it was no good ringing because there was no night staff who could get into the dispensary. It wasn't worth ringing and I just laid in pain all night' (Interviewee, p16).

Lack of personal contact with staff affected participants' wellbeing, quality of life and their ability to make their views heard.

'Sorry to be negative but I find that if you go out you need a carer to come with you and there aren't always carers around that will come with you. They're always tied up' (Interviewee, p16).

'By the time you've waited for them to come back you've forgotten what you wanted to say' (Interviewee, p17).

Some residents felt less than human:

'You're more of a number than a person. You're a commodity. You're just a commodity, nothing else. I mean you're put to bed, you get fed, you get up in the morning and that's it. You can book up to go out but that depends on whether the driver's here or you can get a volunteer which we're very short of' (Interviewee, p17).

'...some of these charitable organisations have in the past been run very much on a 'We know what's best for you' type of ethos and I think that Leonard Cheshire is struggling with this because obviously they have been looking after people with profound and severe impairments ...' (Interviewee, p17)

In these circumstances, empowerment and user involvement in the day-to-day decisions over their own lives can be seen as 'a problem'.

'One of the problems it (user involvement) causes is when residents become more empowered and aware of the opportunities of life they're likely to ask for more. In asking for more, it usually involves staff, and resources are already very scarce and limited, and centred mainly in providing basic daily care in washing, dressing, eating and they occupy an awful lot of time. Empowerment creates problems of staff support. And if the choice of empowerment involves travel then that's a further added burden. Not necessarily to pay the cost of travelling but to have the opportunity with limited transport or escort' (Interviewee, p17).

Understaffing can be used to justify the lack of choice over support staff.

'I do depend quite a lot on support and care from the domiciliary service which is quite good in the limited capacity that they have. There is somebody they send to me that I don’t want but what they say is "Well if you don’t want her we haven’t got anybody else" ' (Interviewee, p18).

'Each one of us has a key worker but they have less and less time to spend on us. There’s less and less ‘one-to-one’ going on' (Interviewee, p18).

2. Transport

Lack of transport and drivers was often mentioned and this has huge implications on their quality of life:

'The transport is very nice but we don’t get out enough. There’s a shortage of drivers' (Interviewee, p20).

'I had an OU thing that I wanted to go to. I arranged it three or four weeks in advance but two or three days beforehand the driver pulled out and I couldn’t go' (Interviewee, p20).

'There’s trips every week but they can only take three wheelchairs in the van' (Interviewee, p20).

‘I waited until half past twelve yesterday, just in time for lunch. I should have been here at ten. It was more or less just for the afternoon session’ (User of day centre, p20).

'What I can’t understand is that they’re a big organisation, Leonard Cheshire, so why don’t they fund it (transport). This is what I can’t understand. Where is the money going? It’s a big charity and we do a lot of fund raising here for Leonard Cheshire and we’d like to know where the money goes. We should be part of it, we should know where it goes' (Interviewee, p20).

Lack of spontaneity and flexibility is also an issue:

'I go out quite a bit and I use transport if I can book it up far enough in advance. You can't be spontaneous' (Interviewee, p21).

3. Agency staff

The residents had negative opinions about agency staff, who they thought of as unskilled, unmotivated and not responsive to their needs.

'They're only in it for the money' (Interviewee, p23).

'They're not interested because they know they're not going to come back here again. It's just a day's work. They're just passing through' (Interviewee, p23).

'It's mostly at weekends that there's a shortfall of our own staff. Agency staff aren't so dedicated' (Interviewee, p23).

Sometimes communication issues exacerbated problems:

'They only understand what they want. They don't listen. There was a chap feeding T. He's a resident, he eats, and he'll eat everything, but when he has a drink he has to have thickener in it because otherwise it goes straight to his lungs. And the bloke's feeding him, and giving him a drink, and T's coughing. He's choking because the drink's going straight to his lungs, and I said to him six times "He wants thickener in it" and all he said was "Stop coughing T" ' (Interviewee, p24).

4. Staff attitudes and behaviour

Most residents thought the staff were doing their best under challenging circumstances. But, some residents described poor attitudes and behaviour, which, in turn, affected how well the service users could control their own lives. Central to this seems to be the power that staff can have in the carer–cared for relationship:

'Yesterday I had a really bad day when I could hardly lift my hands up and he (another resident) was helping me. And they turned round and said "Why aren't you doing that yourself?" and I said "I cannot lift my hands up sometimes". I'd been using the computer and my arms were really aching' (Interviewee, p24).

Service users expressed fear about speaking out and making their views known:

'We can (make views known) through the Disabled People’s Forum and we can through SURE. The only thing is you have to be very careful because if you say too much your name is mentioned and you are put down as a troublemaker...' (Interviewee, p24)

'My involvement with the Disabled People’s Forum, we had meetings locally in our areas, whereby the chairman felt threatened inasmuch as he is disabled and in a residential care home and he was frightened like "If I write a letter stating these things I might be badly treated, I’ll be singled out in the residential care home where I am and I don’t know whether I can cope with that." You get labelled. It’s the old thing: you’re stirring it for others, you’re causing trouble, all those issues’ (Interviewee, p25).

5. Health and safety policy

Residents said that the introduction of an excessively overprotective Health and Safety policy had an impact on the way people could control their lives and eroded their basic human rights throughout the organisation.

'When I came here with my husband we lived in the annexe and we didn’t have to have any assessments. I’m now in a double room on my own and before I can use my microwave I’ve got to have an assessment on it, the same for boiling the kettle. What an insult! I did it in the community but I couldn’t do it here until I’d had an assessment' (Interviewee, p26).

'You can’t go out on your own unless you have an assessment. I find it insulting, very insulting! C said I’ve got another one today. Then you get frustrated. People think we’re imbeciles' (Interviewee, p26).

6. Ability to influence the hierarchy

Most residents felt that the management of the organisation was distant and not interested in their needs:

'We’d like them to come down and speak to us but every time someone comes down they want the questions given to them beforehand, so they can rehearse their answers, or for whatever reason, before they come. They shouldn’t do it like that.

They won't just sit down with you. They're frightened of the response they're going to get' (Interviewee, p27).

Service users had met Leonard Cheshire himself and spoke positively about his personal approach. Some service users felt that the Leonard Cheshire Foundation had changed from 'a family' to a large-scale business organisation:

'Since Leonard Cheshire died you know they've changed a lot really. They like to do things their way now. Of course I knew Leonard Cheshire very well. If anything went wrong we could always go to him and he'd get it sorted out. He ran the whole organisation but now it's become more official. I don't think we have as much control as I think we should have. A lot of people now have never known Cheshire' (Interviewee, p28).

7. Forums and committees

Many people interviewed suggested that the power structures in the organisation's management made the user involvement committees and the Disabled People's Forum ineffective:

'I don't think these committees get anywhere. If they want any changes in this organisation, they send us forms but they've made up their minds anyway so what's the point?' (Interviewee, p31)

8. Training

Training was often specifically mentioned:

'I've been involved in the setting up of NVQs for care staff and also NVQs for service users to be assessors. We get very good training from the DPF. There's courses for committee skills, for DET training. If you can just forget for once the difficulties you are going to have, in getting support and transport. It is well worth it' (Interviewee, p32).

9. Mentoring

The effectiveness of mentoring depends on contextual factors, as expressed by one service user:

'It depends on your region and your relationship with the regional director and your relationship with each home. One home might be really supportive and everyone wants you to come back and another home may see you as a threat. I think for me it's sometimes hard to get respect from staff especially care staff, sometimes I think they feel I'm interfering. They see me as a disabled person. (They are) unhelpful, not friendly, don't listen, brush you off' (Interviewee, p34).

10. Residents without a voice

There was significant worry that people with communication difficulties were not listened to throughout the organisation, between management and service users, and between regions:

'There are people here who can't get their point of view across. They can't talk' (Interviewee, p36).

'A lot of the more seriously disabled people can't speak up for themselves' (Interviewee, p36).

'The reason I speak out is that I'm thinking about the people who can't speak, like H and W, and if things are really bad for us what the hell is it like for them?' (Interviewee, p37)

11. Lack of information about money

Several of the residents were anxious about lack of information about how their fees were paid in the home. This gave rise to a feeling of lack of control in their lives:

'Where is the money going? It's a big charity and we do lots of fund raising here for LC and we'd like to know where the money goes. We should be part of it, we should know where it goes' (Interviewee, p38).

'The organisation is too top heavy. When I came here six and a half years ago, there were forty staff up at head office and now they have ninety. At the same time they reduce the staff here. They take the money away from where it's needed' (Interviewee, p38).

12. Satisfaction with Leonard Cheshire services

Some service users in expressing satisfaction showed little concern about user involvement.

'The thing I appreciate most here is the privacy. You are entirely private in your own room with en suite and it really is a treat' (Interviewee, p38).

'As far as I'm concerned, I mean I can't do anything for myself, I can't get out of bed, feed myself or do anything, I can't do anything to do with cleanliness, and I do find that they do it very well. They take care of you and do everything. And then we have lots of things to do, a lot of entertainment and we're taken out. It takes your mind off how you are really. In that respect I find it's very good. I've only been here a year and a half, but I find that they have been very good to me' (Interviewee, p38).

Findings from Stage 2 - Case studies

Five case studies were conducted, which varied in scope and focus but the purpose was to document 'good practice', or changing practice, within Leonard Cheshire. Below are selected quotes from case studies where user views are evident.

1. Case study 2 – Ponteland Independent Supported Living – Bradbury Court

The researcher carried out interviews with 4 residents. Service users saw Independent Supported Living as a very positive change in terms of services. The tenants experienced increased user involvement and more control. All tenants have individual social workers and care managers.

i. How service users felt about independent supported living and how they handled change

A service user was asked how she felt about the changes in living situation:

'There wasn't enough time to take in what the changes were. They didn't give us the down side of it. They just talked about the positive side of it all the time' (Service user, p68).

When asked about the challenges, one service user said:

‘We weren’t told about how much responsibility would be put on our shoulders, on my own shoulders’ (Service user, p68).

‘I am responsible for my own money which makes it feel more feel like you are in control of your own life more’ (Service user, p69).

‘Now that I live in Independent Living I get to keep all my benefits you see – so I get a lot more money. I can save my money up and go on holiday where before I couldn’t afford it. The financial benefit is the main thing’ (Service user, p69).

ii. Personal Assistants

Personal Assistants (PAs) made a significant difference to tenants' lives:

‘We have support to go out and do something normal and not go out with a great big group’ (Service user, p69).

‘I feel I have got control of my life. I can plan what I want to do especially if I do it in advance. I thought of having a dinner party, but I wasn’t very well for a while but next year I will be able to start doing that. They will help me to cook and they’ll help me to plan a dinner party if I plan a little bit in advance. I sort of feel that I’m living in my own home, that my room’s treated as my own home and I make my decisions about what I want to do’ (Service user, p69).

2. Case study 3 – DPF and The Learning Difficulties Service Edinburgh

Interview with service user who has moved to Independent Supported Living (purchasing a Learning Difficulties care package) after moving out of a Leonard Cheshire residential home:

‘I found it very hard. I was looking for somewhere to live for 5 years but I couldn’t find one because there were other units I could go to but they said I was too handicapped and one said I was not handicapped enough. So then I got me place at [Leonard Cheshire] and been there ever since’ (Service user, p74).

Asked about support:

‘Yes, I have a support worker. She is called M and she is absolutely fantastic.’

‘She stays. I am in supported accommodation, which means there are support workers already there. I am with seven other people.’

‘Yes I have my own house. The support workers are there if we need them’ (Service user, p74–5).

On the question of control, she said:

‘Oh yes now I do. I have got my independence. It’s great because now my mum doesn’t have to worry about me and I don’t have to worry about her (her mum has diabetes)’ (Service user, p75).

Considerations: Content is meaningful up to a point in that it appears to reflect general messages about service user involvement in services. However, service user views (from stage 1 of the evaluation) do not distinguish who is making a statement or in which settings these are based, therefore it is difficult to draw any conclusions without this vital context. The authors do not refer to peer review. They make reference to the management of the project being undertaken by a Steering Committee whose role was to ensure the evaluation remains independent and that the research is collaborative, 'that is conducted ‘with’ rather than ‘on’ the organisation' (p6).

Trappes-Lomax T and Hawton A (2012) The user voice: older people's experiences of reablement and rehabilitation.

Methods: Semi-structured face-to-face interviews.

Data: Views of rehabilitation services in community hospitals and local authority short-term residential units.

Country: England, UK.

Setting: Community care services and intermediate care/rehabilitative.

Scoping framework areas: Continuity of care transitions; care and support of people’s needs.

This report presents analysis of data from an overall high (++) quality survey study. The study aimed to report the voices of older people describing their experiences of what service users thought worked well or could work better about rehabilitative care.

Sample size: Semi-structured face-to-face interviews in 2002/03, with 42 participants (mean age 81.4 years) using interpretative phenomenological analysis (IPA).

Analysis: Data was analysed using a systematic analysis of common themes arising from the transcripts. Carer transcripts were coded separately. The coding was checked in two stages by an independent researcher and a research psychologist. The last stage involved sending interviewees a summary of results and asking for feedback on this. Seven replies were received, which provided further detail on individual experiences, but none conflicted with the feedback.

Findings

Four main themes emerged:

1. The complexity of rehabilitative need

The authors comment that most goals in the community hospitals were about personal care skills and mobility, as exemplified by the following quotes:

‘To manoeuvre from the chair to the toilet was . . . quite difficult. It doesn’t seem so now of course, but it was then’ (Participant, p186).

‘We have a very difficult staircase (at home). I used to practise walking up and down’ (Participant, p186).

The above was in contrast to the rehabilitation units, where the authors say the main aim was on regaining independence and confidence:

‘I was determined I wasn’t going to stop like it (bedbound) ... I was such a nuisance to everybody’ (Participant, p186).

Goals for participants were very practical, for example:

To ‘do my own shopping and washing ... be able to use my legs again, that was the main thing’ (Participant, p186).

Participants implied that hospital routines tended to emphasise dependence felt during periods of rehabilitation, for example:

‘Everything was done for you… When it was time for me to come home, they were still trying to do everything for me ... And that really got my goat’ (Participant, p186).

In the rehabilitation units, the authors say people welcomed the chance of doing things independently, for example:

‘They wanted us to do as much as we could ... you could go in the kitchen and get your own tea’ (Participant, p186).

The authors say most participants welcomed this independence:

‘(After hospital) you need ... somewhere like that to give you confidence and think . . . I can do that at home’ (Participant, p186).

When asked how the care process could be improved, participants told the authors that mobility was a priority for most people in hospital, with almost every response expressing the need for more physiotherapy. However, some responses were more complex and participants differentiated between physical and psychological progress, as exemplified by this quote:

‘They talked about more purposeful and practical daily activities in the residential units: “If I’d been taught a skill – that would have interested me a lot”’ (Participant, p186).

In both clinical and non-clinical settings, participants said they would have liked more chances to talk to someone who understood what they were going through:

‘Deep down inside me I know life will never be normal again’ (Participant, p186).

‘But they said that staff rarely had time to talk as they were usually “busy doing other things”’ (Participant, p186).

2. The effect of different settings

The authors highlighted the need for regular re-assessment and a diverse range of activities, irrespective of the setting. Community hospitals were valued by individuals for their small size, and for being local and having a friendly atmosphere, as exemplified by these quotes:

‘It was near home’ (Participant, p187).

‘There wasn’t the rush that there had been in the (acute) hospital ... all so free and easy really’ (Participant, p187).

The authors comment that participants said they often made most progress in regaining basic skills, mobility and confidence in the community hospital, for example:

‘Making me do things I’d never done before! You really felt something was happening at last’ (Participant, p187).

However, the smaller rehabilitation units are reported to be better able to promote mutual support and re-adjustment to ‘ordinary’ living, for example:

‘You made your own pot of coffee. You didn’t think you could manage it but you did ... you felt you’d achieved something at last. Yes, that was the start of the rehabilitation’ (Participant, p187).

The main disapproval of the community hospitals was the lack of things to do. When asked about a typical day, most people reported long stretches when they:

‘…just sat beside the bed for countless hours and nothing was happening’ (Participant, p187).

3. The dual role of staff

Study participants described both ‘hands-on’ and ‘hands-off’ approaches, for example, used in motivation techniques:

Indirect: ‘You don’t realise the back-up that was there all the time. You think you’re doing it all, but you’re not’ (Participant, p187).

Or

More direct: ‘When you’re not feeling well, you can’t be bothered ... you’ve got to be pushed a little bit. Otherwise you just sit back and think, ‘Oh I don’t care’. Although you know in your mind it’s the wrong thing to do, your willpower won’t do it’ (Participant, p187).

In the rehabilitation units, the authors report that recovery was often promoted through collaboration:

‘Tis up to me whether I can do it ... or whether I take in what they say ... Tis a partnership, yes, yes. If one don’t want what the other one (wants) ... it’s no good. But if I think they’re good, then it works together’ (Participant, p187).

4. Life back at home

This theme relates to participants’ experiences of transition from residential to community-based care. For patients going home straight from a community hospital, there was evidence of good preparation:

‘I had this punishing training on the stairs and knew I could actually do it once a day, so I did want to come back’ (Participant, p188).

But there were also examples of apparently unplanned discharges:

‘Nobody seemed to know what I was going to do – me less than anybody’ (Participant, p188).

‘A woman brought me home – she just dropped me in and that was that’ (Participant, p188).

Several people said a one-off phone call or nurse visit would have helped when they first went home from hospital:

‘Part of the fright of coming home was that you were completely on your own (when) you’d had a doctor every day and nursing staff all the time’ (Participant, p188).

The authors report that once home, there were continuing problems in terms of pain or physical limitations, lack of rehabilitative input – almost no-one had received any therapy once they returned home, either from hospital or from a rehabilitation unit – and a lack of ‘enabling’ support either from the statutory or voluntary sectors:

‘I got no help whatsoever, only a list of telephone numbers and ‘you don’t meet our criteria’ – it makes you a bit resentful’ (Participant, p189).

One or two people reported high levels of personal care, but with some misgivings.

‘You never know when they’re coming, you never know who’s coming’ (Participant, p189).

Family and friends were described as having to make up for any poor levels of formal support received by participants.

Considerations: This is overall a good quality study. The authors state that findings mirror other studies of user experience and related evidence about assessment, institutionalisation and psychological factors. The narrative is full of rich quotes from service users where contexts of the data are clearly described.

Valdeep G, Husain F, Vowden K (2014) Satisfaction with social care services among Black and Minority ethnic populations: exploring satisfaction with adult social care services amongst Pakistani, Bangladeshi and white British people.

Methods: In-depth interviews and focus groups.

Data: Views of social care delivered by BME groups.

Country: England, UK.

Setting: Community care services.

Scoping framework areas: Care and support for people’s needs.

This report presents analysis of data from an overall medium (+) quality qualitative study. The study aimed to provide explanations for the reasons behind lower levels of satisfaction of social care service delivery among Pakistani and Bangladeshi groups. White British people were also included as a comparison group. In-depth interviews and focus groups explored whether lower satisfaction was related to how social care is delivered to or received by black and minority ethnic groups.

Sample size: The sample was selected to ensure representation of both men and women and different ages (18 to 59 years or 60 years and over). People who were either in the process of applying for social care at the time of interview or had been in receipt of care in the previous 12 months. The sample included people who were in receipt of personal budgets. Sixty-one service users were interviewed. Additionally, 24 social care providers were included in the research.

Analysis: The interviews were transcribed verbatim and analysed using the Framework method, developed by NatCen. Framework is a qualitative data analysis method, which uses a 'matrix' approach to conduct theme and case-based analysis. In carrying out analysis of qualitative data, the authors ensured that the analytical framework was grounded in the data and not imposed by the research team, and was one which met the study objectives.

Findings

Pages 40–49: In the section titled 'Service users' views of what local authorities offered them', some service users spoke about social care providing social contact and companionship for them, for example:

'There are people [professional care workers] that really take care of me here and may Allah bless them and the biggest problem is the loneliness, it is killing me' (Service user, woman, Pakistani origin, London, p43).

Those who were socially isolated were also reliant on their care worker for regular social interaction:

'I mean that's probably the highlight of your day' (Service user, man, white British, Leeds, p52).

Page 50 – In the section titled: 'Receiving care', the authors describe service users expecting care workers to be both professional and personable. For example, one service user said:

'I think it's important that, there [are] three attributes. One is punctuality, two is the rapport and three is getting the work done properly. She's [my care worker] got all three. If you haven't got all three, then it might be a problem' (Service user, man, white British, London, p50).

The authors comment (pages 50–51) that there are challenges in reaching a good balance between service users' expectations and delivery:

'Some service users and relatives had unrealistic expectations of care workers duties, for example, an expectation that care workers could do tasks outside the agreed care plan. Secondly, care workers had pressurised workloads, resulting in having to rush or struggle to complete all tasks in the given time.' For example, one service user described her dissatisfaction at having her care worker refuse to do things outside of her care plan: 'I have had carers who sort of said, "It's not my job", and flounced out leaving me without bread and milk at the weekends' (Service user, woman, white British, London, p52).

The authors go on to comment that service users expressed dissatisfaction over the late running of care workers and that unexpected lateness, in particular, caused anxiety for service users and was frustrating for relatives who relied on staff for assistance and respite. For example, one service user said:

'You're looking at your watch and one o'clock comes and they're not here and two o'clock comes and they're not here and you start then to get anxious. Are they gonna come, aren't they gonna come?' (Service user, man, white British, Leeds, p56).

Service users were asked about 'matching' (for example, a care worker with the same ethnicity as the service user). This was considered to be a lesser priority:

'They are here to do a job. When we go to hospitals we can't expect staff to be Muslims or from the same background as us' (Service user, man, Pakistani origin, Leeds, p63).

The authors comment that:

‘Family members expressed more concern about ethnic matching than service users’ (Authors, p71).

The authors report that there was a general dissatisfaction with meal on wheels services, with the main issue being poor quality foods being provided at a high cost. For example, one service user said:

‘They're charging £4.10 pence for a dinner in which there's a tiny pudding which you wouldn't feed to a dog, to be honest, but now, because [the] Council has removed their subsidy, they're going to go up to £5.71’ (Service user, male, white British, Birmingham, p66).

Page 68: The authors conclude that:

‘Service users taking part in this study clearly suggested that the interplay of culture and religion influenced their level of satisfaction with social care. This was mainly expressed with reference to the attitudes and beliefs of older service users’ (Authors, p68).

Page 69: The authors conclude that:

‘Dissatisfaction was experienced when local authorities and care workers did not consider the needs and contribution of other family members when providing care’ (Authors, p69).

Page 70: The authors conclude that personal budgets received through direct payments:

‘…were a potential source of satisfaction for Bangladeshi and Pakistani service users and their families since they allowed care to stay within the family or the community’ (Authors, p70).

However, they note that they could also be a source of dissatisfaction because of the difficulties of managing them.

Page 70: The authors conclude that language was a barrier for many service users and their families in terms of accessing care, which they say necessitated good levels of English in order to get the right services arranged.

Page 73: The authors comment that culturally appropriate care was relevant for those participating in activities outside the home, for example at day services. For example, service users expressed more satisfaction if activities such as exercise classes were segregated by gender.

Pages 74–78, key author recommendations included:

1. Having frontline local authority staff with relevant language skills; navigating the social care system could be made easier for people by having a policy of user friendly language across all areas of the system – from websites to assessments.

2. Promoting direct payments and personal budgets, in particular, was suggested as a way to engage black and minority ethnic groups with social support services.

3. Local authorities should provide 'Cultural awareness training'.

4. ‘Local authorities should have a policy of not using family members as interpreters within assessments and meetings with social workers; to avoid misinformation, and breaching confidentiality of service users’ (Authors).

5. ‘Service users and families may benefit from training (provided by local authorities) to provide information on the role of care and support worker and care plans, and information on issues such as how to make a complaint’ (Authors).

Considerations: The study was not grounded in any theory. Purposeful sampling was conducted. The sample locations were selected to capture variations in socio-economic status and local and regional differences in terms of provision of social care. The researchers chose areas with large Pakistani and Bangladeshi communities using data available from the Office for National Statistics and deliberately chose two areas with a higher concentration of people of Bangladeshi origin and two areas with more people of Pakistani origin. Although the initial sampling criteria included specific local authority areas (Newham, Redbridge, Birmingham and Leeds), this was later relaxed to include other areas within London. During recruitment compromises were made in relation to some criteria (such as area) and final interviewed numbers interviewed. The intention had been to conduct two phases of research: interviews with service users and then follow-up interviews with a relative. However, the interviewing of relatives was later dropped. In most instances it is clear how conclusions link up to the findings sections but this is not true for all of the conclusions. Although there is a reasonable amount of direct user views many of the interviews were proxy, carried out with the participant's relative.

These summaries include the video evidence, which was reviewed together with the additional evidence.

Westwood S (2016) 'We see it as being heterosexualised, being put into a care home': gender, sexuality and housing/care preferences among older LGB individuals in the UK.

Review Question: 1

Methods: Semi-structured interviews.

Data: Views relating to participants' concerns about health and social care provision.

Country: England.

Setting: Own home.

Scoping framework areas: Personalised support; Care and support for people's needs.

Population group: Lesbian, gay, bisexual, queer, and transgender, older people.

The study rated low (−) quality, aims to find out what choices older lesbian, gay and bisexual individuals would like to make about sheltered housing and residential or nursing care provision for themselves, given that some choices are not currently open to them, for example there was no specialist lesbian, gay and bisexual provision, unlike some other developed countries where there is a growing number of specialist retirement facilities. The study aims to analyse 'their concerns about mainstream sheltered accommodation and residential care, in terms of lack of visibility, risky visibility, unequal openness and compulsory co-occupation. It considers their differing sheltered housing/care preferences and the significance of gender for those preferences. The legal and social policy implications are considered' (p156).

Sample size: 60 participants – 36 women, 24 men. From the sample of women, ‘29 identified themselves as lesbian, one as gay, two as bisexual and four (all in civil partnerships but previously in heterosexual relationships) were uncertain and/or unwilling to assign a label to their sexualities' (p156). Such detailed information is not provided about how the men identified their sexual orientation, although due to the nature of the research it must be assumed that all were gay or bisexual. Ten of the 60 participants were living in sheltered accommodation. The remainder lived in independent accommodation, but were within an age range where they may have been considering the sort of supported accommodation they might prefer as they grew older. All but one of the participants was white British. The ethnicity of the one who was not white British is not stated.

Analysis: The analysis was carried out using thematic approaches, which is appropriate to the methodology. Themes were identified according to the ‘frequency of their presence; for the significance placed upon them by (some) participants; for the ways in which they complicated one another; and for their saliency and significance’ (Buetow 2010, p157). There is no mention of the researcher's analysis being checked by any other parties.

Findings

Participants felt that older age housing/care spaces were intrinsically heterosexual:

‘We see it as being heterosexualised, being put into a care home’ (Female participant, aged 60, p157).

A male member of his local day centre committee for older people, would refrain from using this service:

‘So although I’m actually supporting this heterosexual day centre, because of the need for it, I’m also trying to find alternatives for gay people ... Because I can’t see me fitting into somewhere like that... it’s all geared to heterosexual people…Everything that happens, what they talk about, and their past, things that don’t relate to me as a gay man ... Everything’s heterosexist, really. They can’t relate to your needs ... You don’t have ‘Gay Times’ on the table, but you’ll have something for heterosexuals on the table' (Male participant, aged 65, living in sheltered accommodation, p157).

Concern was voiced about both care standards and 'dominant heteronormativity' ('a lot of straight people singing Second World War songs'):

'I don't want to be sitting in a urine-smelling older person's home with a lot of straight people singing Second World War songs. I'd rather be sitting with people that I can relate to, watching gay cabaret, or getting some of the LGBT film festival films coming in, you know, that sort of thing' (Female participant, aged 60, p157).

Concern about abuse was raised:

'Because of our sexuality there's more to be abusive about potentially and because we're still considered less than, then the idea of stealing from us, or you know being abusive in some other way, is even more attractive. Well who cares about the fag, who cares about the dyke, they don't need the money, so in that sense we're more vulnerable' (Participant, aged 66, p157).

Of even greater concern among participants was everyday homophobia. One female participant spoke about a friend living in sheltered accommodation, who is not open about her sexuality:

'... she lives her life privately. But she has to get involved in this sheltered unit, because there are coffee mornings and things like that and, you know, she doesn't want to be unfriendly. She wants to feel part of that community. She also happens to be Black. And she's had to listen to things, when people have been reading the newspaper, listen, when there's some gay issue or something, to things like "Oh, if my daughter was like that I'd kill her". Now what does she do with that? If she challenges that she outs herself and then puts herself in a very vulnerable place' (Female participant, aged 69, p158).

And this issue carried over to perceptions of care staff attitude:

'What if they [care staff] took a dislike to me? I don't think many people here would understand it or accept it somehow' (Female participant, aged 92, living in sheltered accommodation, p158).

Lesbian, gay and bisexual individuals ‘continue to live in fear and hide their identities’ in care spaces as echoed in the following quote:

‘Be nice if you could have your partner’s photo up, or have a place where you can be private together, or even, in a public place, hold hands without it being nudge-nudge, wink-wink’ (Female participant, aged 69, living in sheltered accommodation, p158).

In terms of care preferences, the majority of participants said that there should be a choice of provision, for example:

‘I would like to see a choice of care homes’ (Female participant, aged 63, p159).

‘I think people should have choice . . . and there should be homes for gays and lesbians definitely’ (Male participant, aged 66, p159).

Participants who preferred mainstream provision stressed the importance of integration and wanting to avoid segregation and ghettoisation:

‘I think care homes ought to be integrated otherwise you’re going to get segregation’ (Female participant, aged 69, p160).

‘I don’t want the LGBT community to be ghettoised. When I want extra care, I wouldn’t want to be with just gay men. I’ve always seen myself as part of the wider community and want to remain there. As a gay man’ (Male participant, aged 70, living in sheltered accommodation, p160).

The study concludes that there are a 'wide diversity of care concerns and preferences among older LGB people' (p161). A range of preferences were expressed, for living in accommodation that would be women only, lesbian only, men only, gay men only, lesbian and gay or lesbian, gay and bisexual or lesbian, gay, bisexual and transgender exclusively, or integrated provision. Ageing and sexuality were concerns for all, with gender considerations also being more significant for female participants.

Considerations: Only 10 out of 60 interviewees are described as being service users, that is, they live in sheltered accommodation. The remainder are expressing their preference for the type of service (supported housing provision) they would like if and when they need it. The study does provide information about what lesbian, gay and bisexual service users would wish if they entered elderly residential care, and how it could be ensured that the right care was delivered to them so that their social and emotional needs and wellbeing were supported. The study was self-selecting, as recruitment was carried out using online advertising, social networks, opportunistic and snowball sampling. Although for qualitative research, representativeness is not of primary importance, it is worth noting that the sample does seem particularly weighted in some areas. Only 1 out of 60 participants were non-white, the majority were described as being 'well educated and relatively affluent' (p156).

Willis P, Maegusuku-hewett T, Raithby M, Miles P (2016) Swimming upstream: the provision of inclusive care to older lesbian, gay and bisexual (LGB) adults in residential and nursing environments in Wales.

Review Question: 1

Methods: Data collection was carried out by conducting semi-structured interviews with the lesbian, gay and bisexual people in their own homes. Five focus group interviews with care and nursing staff and managers were also included but not reported here.

Data: Views of prospective service users about how they anticipated good care should look if they were to move into residential care.

Country: Wales.

Setting: The settings under consideration are adult social care residential homes for older people.

Scoping framework areas: Respect, dignity and control; personalised support; care and support for people needs.

Population group: Lesbian, gay, bisexual, transgender, and queer, older people.

This study rated medium (+) quality, uses interviews with lesbian, gay and bisexual people who are prospective users of residential and nursing homes, and with staff and managers of residential and nursing homes, to explore how these places provide heteronormative environments13, and how this could be addressed to ensure they provide suitable environments for older people with diverse sexual identities.

Pugh (2012) discusses the concept of ‘care anticipated’ to capture the ways in which lesbian, gay and bisexual individuals look ahead to the future and identify priorities and expectations for care based on their own biography and life experiences (Authors, p289). The research interview protocol had a similar future orientation, which included questions about how respondents would like to be treated by health and social care staff if they moved into residential care. Three focus group interviews were conducted with 14 care staff, and two focus groups were held with the 27 managers. The focus group sessions lasted 45 to 90 minutes, and were co-facilitated by two members of the research team.

Sample size: Lesbian, gay and bisexual adults interviewed were recruited using purposive and snowballing methods, that is, they were self-selecting. The authors state that as there is no census data about the numbers of lesbian, gay and bisexual people in the UK, a representative sample would be impossible to achieve. However, this does mean that certain voices or perspectives could be absent, most notably, since all interviewees are white.

Twenty-nine service users in the interview sample contained 19 women and 10 men, of whom 1 identified as a cross-dressing male. Twenty-three service users were aged between 50 and 69 years, and 6 were aged between 70 and 76 years. All service user participants are identified as white, with 26/29 'of British descent' (p290).

Analysis: The study reports that for service user interviews 'Transcripts were thematically coded in NVivo using an interpretative phenomenological framework whereby the focus was on the participant’s understanding of their social world, identities and expectations of future care. During the analysis we were mindful of not obscuring attention to the heterogeneity of older LGB people’s lives – ‘we do not want to convey an artificial image of participants’ lives as following uniform

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[13] Heteronormativity is ‘the institutionalised assumption of heterosexuality as a normative social marker’ (Authors, p285).

trajectories and neglect differences on the basis of other social identities such as age, gender and ability' (p289–90). NVivo was also used to analyse the transcripts of the focus group interviews with practitioners, and the study describes how themes emerged from the interviews, with team members checking each other's analysis.

Findings

Key findings: The study compared the expectations of lesbian, gay and bisexual people about future residential care provision with the reality of what was described by managers and staff currently working in residential care settings. Staff and managers did recognise care homes as 'sexualised spaces in which staff and residents are frequently engaged in intimate interactions across a number of domains' (Authors, p299). However, 'care environments are seen as hetero-sexualised spaces in which the discussion and expression of non-heterosexual identities and sexual practices is glaringly absent…non-normative sexual identities are located as separate or irrelevant to providing care to others; and care is framed as sexually neutral' (Authors, p299). As a result, lesbian, gay and bisexual identities are largely invisible. This situation was reflected in feedback from many of the interviews with lesbian, gay and bisexual older people who disliked the potential situation of being presumed to be straight by care staff:

'I don't want people making jokes about boyfriends, you know, and "what did your husband do dear?", yes, I suppose that's what it's about really, just the same as now when I have a conversation with somebody I don't want them assuming that I'm straight... and it's the same for when I'm old and needy' (Female participant, p293).

Equally, several participants expressed concerns about having to go 'back into the closet' if they moved into a care home:

'I suppose I can't imagine being in a place where everybody around you would not know that you had spent all of your life as a lesbian, I mean that would be, there is no point in living, that would be the worst thing for me if you had to be completely in the closet with nobody knowing about you and you couldn't talk about your life…' (Female participant, p293)

A number of women expressed fear of losing control over their personal dress and appearance while in the receipt of care, sharing living spaces with men residents or having intimate contact with men carers. This was particularly so for some lesbian and gay women who had very little contact with men and were dependent on mainly women-only networks within their local communities:

'…and again I think it is about being a woman, somebody of the same sex, I wouldn't want a man coming in to give care... I'm sure that's the same with a lot of women, it's not just a lesbian thing, it's about just feeling more secure with another woman as opposed to a man, that's important…' (Female participant, p294).

Over half the sample (13 women, 2 men) expressed a preference to live in lesbian, gay and bisexual-specific facilities. These were 'imagined environments in which heterosexual norms and assumptions would not feature in the delivery of care and participants could anticipate feeling safe and valued as LGB adults' (Authors, p294).

'…my ideal in terms of care would be to be in a sort of sheltered accommodation that was just for lesbians ... because I wouldn't particularly want men around, to be honest, gay men or straight men' (Female participant, p294).

This description by staff and managers fitted with the expectations of lesbian, gay and bisexual prospective residents, who had experienced homophobia across the course of their life. However, although lesbian, gay, bisexual, and transgender-specific retirement homes operate in some other European nations and some US states, the authors report that this would run against the implementation of the 2010 Equalities Act which requires providers to supply a non-discriminatory service, and recommend that instead care staff and providers 'need an understanding of discrimination endured by LGB individuals across their lifecourse and how this impacts on LGB individuals' present and future interactions with health and social care professionals' (p300).

Considerations: The prospective service users who participated in the study do not have experience of the service about which they are being interviewed. The study could have benefited from including some voices of lesbian, gay and bisexual people actually living in residential care. However, the authors comment that given the heteronormative environment described in these places, it could have been difficult to identify lesbian, gay and bisexual people resident in them who were open about their sexual identity. And although this could have added another dimension to the study, the authors argue that the study still 'works' by giving voice to what the group of lesbian, gay and bisexual people interviewed would want from residential care, and then juxtaposing that with practitioners' descriptions and the findings from other studies. The authors also mention their difficulty in accessing older bisexual adults, despite attempts to counteract this through snowball sampling and by contacting bisexual communities online (Authors, p290).

Willis R, Khambhaita P, Pathak P et al. (2016b) Satisfaction with social care services among South Asian and White British older people: the need to understand the system.

Review Question: 1

Methods: In-depth interviews with South Asian and White British service users and family carers, the majority of whom were older people.

Data: Experiences of satisfaction with social services.

Country: England.

Setting: 'Interviews were carried out at a place and time convenient to the participant, e.g. the participant’s own home, their day centre or the university' (Authors, p1369).

Scoping framework areas: Continuity of care and transitions; care and support for people’s needs.

Population group: Lesbian, gay and bisexual, older people.

This qualitative research study rated medium (+) quality examined the experiences of people from South Asian and White British backgrounds with social care services and the reasons for satisfaction.

Sample size: Eighty-two: 46 service users and 36 family carers. Thirty-nine practitioners also interviewed, but their data was not part of this research paper. Thirty-nine South Asian, 43 white British. Various religions including Hindu, Sikh, Muslim and Christian. Service users: 25 to 90, modal age category 70 to 79. Family carers: 18 to 82, modal age category 60 to 69. Thirty-nine service provider/practitioners were also interviewed, but those data are not the focus of this paper.

Analysis: NVivo software was used to assist with the process of coding the interview transcripts. 'Two members of the research team coded the interviews, held coding meetings and revised the coding strategy. After coding, themes were proposed and tested in the data. Analysis meetings with the whole research team refined the themes, and the team collaborated in writing up the findings. Themes were discarded if they did not have enough evidence to support them. Other themes were strengthened and amended through the process of exploring the data, and discussion within the team' (p1370).

Findings

The authors report that the main theme that distinguished satisfied from dissatisfied participants was an understanding of the social care system. The authors discuss that this theme was more important than ethnicity in explaining reasons for satisfaction. The authors also reported continuity of care and good workforce skills as important factors in satisfaction ratings. The authors report that social care experiences were ‘broadly similar’ among the White British and South Asian participants.

Understanding of the social care system: participants were reported to have a good understanding of how social care services were organised, funded and operated. These participants associated problems with structural factors rather than with individuals, for example:

‘I think the actual provision of these services in most cases is very good and the carers do a very good job under very difficult circumstances with a very wide spectrum of needs and personalities of the person they’re providing the care for. It’s just the whole red tape and the amount of paperwork, how it’s funded is always seen as an issue’ (Participant – carer, p1371).

In contrast, the authors argue these dissatisfied accounts show a lack of understanding about the system:

‘Well, I used to go to [day centre] … And they’ve taken on different people–I had a letter to say I was not suitable to go. And I think they’re taking people that take a while to learn things–have difficulty in learning–and are paying to go there. I don’t know much about it, really. All I know is I had a letter to say I can’t go’ (Service User participant, White British, p1371).

‘So that lady told me, that, sorry, she says, you are not physically disabled or anything. You can do all that, so we can’t take you as a member [of a carers’ group]. I said why not? If all people are coming here then why are we not?’ (Service User participant, South Asian, p1371).

Working with the system: The authors use this quote to demonstrate that you need to know the right question in order to ask for help.

‘The next participant could be said to have asked for help but not received it, because they did not ask in the right way: Some magic wording … we don’t know. How did they get that? I don’t know (laughs)’ (Service User participant, South Asian, p1372).

And this quote to demonstrate knowledge about what is available for service users to access is crucial:

‘There are so many things they [social services] provide, but we don’t understand what is available and what is not available. There must be so many things we don’t know yet. We don’t know what we are entitled to or not. How can we get things if we don’t know they exist?’ (Service User participant, South Asian, p1372).

Continuity of care: As this account exemplifies, it was important to services users that case workers and carers know their cases before visiting:

‘We’d like it to be the same people but they aren’t and you have to explain what’s got to be done and what’s not got to be done, which isn’t a good thing in my reckoning. I think it would be better if we had the same people looking after you all the time and they know what’s what and what’s good for you and what’s not. Because one carer came in and put a lot of soap in the water and it brought my skin up something terrible, only because of not looking into things properly' (Service User participant, South Asian, p1375).

Workforce skills: Accounts in this section demonstrated that having carers with adequate skills was considered important, for example:

'The staff are really, genuine caring, genuinely caring people and again you see, for elderly people that's so reassuring' (Service User participant, South Asian, p1376).

And the authors comment that while professional and interpersonal skills of social care staff were discussed positively and negatively by many White British participants, these skills were less discussed by the study's South Asian participants.

Issues specific to Asian participants: the authors discuss how having culturally appropriate care is important to service users – even just checking if service users require anything specific:

'I will say that upon assessment I was asked whether there are any specific cultural needs that needed to be noted, i.e. did I need to be in contact with my local Gurdwara [Sikh temple] or whatever it was that I needed' (Service User participant, South Asian, p1376).

'Like in [daycentre] there was a quiet silent room that you would need for prayers and I appreciated that they gave me a room for prayers' (Service User participant, South Asian, p1378).

The authors conclude that:

'Developing a good understanding of the social care system is central to satisfaction, so it is worth considering how membership of a minority ethnic group relates to opportunities for this development' (Service User participant, South Asian, p1379).

They also comment that the link between language and low satisfaction was strong, with South Asian participants requesting language needs to be met but this did not necessarily have to be through ethnic matching or through the provision of culturally specific services. The authors point out that language matching is not the same thing as ethnic matching. Having said that, they argue that there is a need for culturally specific services, especially to meet dietary requirements.

Considerations: The authors note that study results are not fully generalisable to other local authority areas. Although a variety of religions in South England were represented, the proportion of lesbian, gay and bisexual people in these areas was low. The research fellow recruited for the study spoke two of the relevant South Asian languages (Hindi and Gujarati), which was essential for recruitment and data collection, but other relevant languages (for example, Punjabi) were not spoken by our research team. Nonetheless, participants included members of different South Asian groups, including Indian, Pakistani and Bangladeshi. Therefore, this study allows for the voices of these ‘"seldom heard"’ groups of service users to be included in the debate’ (Authors, p1383).

Yeung EYW , Partridge M, Irvine F (2016) Satisfaction with social care: the experiences of people from Chinese backgrounds with physical disabilities.

Review Question: 1

Methods: Individual semi-structured interviews and focus groups were conducted in 2012 and 2013 respectively with people from Chinese backgrounds.

Data: Experiences of receiving social care for a physical disability from the perspectives of Chinese adult social care service users.

Country: England.

Setting: Own home.

Scoping framework areas: Continuity of care and transitions; care and support for people’s needs.

Population group: Black and minority ethnic groups, people with a disability.

The study rated high (++) quality began with semi-structured individual interviews with Chinese people who use adult social care services, and then took the findings from these interviews to focus groups so that the researchers' interpretation of them could be validated and clarified.

Sample size: The sample was recruited by sending recruitment material to all local authority adult social care teams and distributing leaflets and posters to Chinese community centres and supermarkets in major cities. Most recruits came through the Chinese community centres, with some recruits contacting the research team directly. Most of the participants were immigrants from Hong Kong, mainland China, Malaysia and Singapore. Their physical impairments were the result of a stroke or other long-term illness such as multiple sclerosis or Parkinson's disease.

Analysis: The researchers ensured they accurately captured what participants were saying by inviting the participants to attend focus groups where the researchers' initial analysis of the individual interviews could be discussed. The interviews and focus groups were recorded and transcribed, with data analysis being carried out in the language used in the original interview, to ensure that meaning was not lost in translation. Thematic analysis of the interviews used the words that were used in the interviews in coding them. The bilingual researchers then translated Chinese codes and themes, with constant reference to source material to ensure accurate representation.

Findings

Although participants were struggling to manage with their physical impairments, they often had to manage for long periods with limited support from their family and friends' networks before accessing social care services. They were unaware of how to access services, which often did not kick in until there was a crisis such as hospitalisation. For example, one participant says:

'My wife is the main carer. She wants to visit her family in Hong Kong but she can't, she cannot leave me alone. There are only two of us. If she goes, I cannot manage' (Service user participant, p150).

Using culturally specific services was discussed as important to Chinese service users as exemplified by these accounts:

'If there is Chinese staff helping me, that's much better. At least we can understand each other. However, there is nothing I can do; I am pleased with the service they provide' (Service user participant, page e150).

‘At the moment, there are people from the Chinese Association, they really help me. I am fortunate to have them to help me. Otherwise, it’s a headache’ (Service user participant, page e150).

Language was a significant barrier to receiving services if literature about services was not available in their mother tongue, which is why services were often not accessed until crisis point. Social workers found it difficult to arrange independent interpreters, and there were some concerns about the quality of translation where people from participants' social networks did the interpreting. For example, one participant in hospital described not understanding the role of the social worker:

‘I didn’t know she was a social worker, I didn’t know what social worker did. My boss’s wife interpreted for me . . . but at the beginning; I didn’t understand anything they said. Actually the social worker found the boss’s wife didn’t translate everything for me’ (Service user participant, p148).

Participants who spoke English were more aware of their entitlements and found it easier to navigate the system and challenge bad practice, but still found the bureaucracy difficult to deal with.

Authors report that service users were heavily reliant on Chinese welfare organisations to meet their social and dietary needs:

‘I like going to the Chinese community centre for recreational activities such as Tai Chi, Mahjong (a game originally from China and is played by four players)’ (Service user participant, page e150).

‘In the care home, they only have western food. They give me a few chips and cold salad. The chips are very dry and I have to drink water to swallow them. I want our hot soup’ (Service user participant, page e150).

‘Our food is different from theirs (the English). At the end of the day, we are not used to what they eat. We like rice porridge, rice, noodles’ (Service user participant, page e150).

Although some participants were very happy with the services they received, some described care staff as uncaring, and all three living in care homes complained about the services they received, with one finding the staff in her care home 'frightening'. The authors report that participants were reluctant to complain, as they felt they were not entitled to better services and were worried about reprisals.

Some families did not ask for help because they were concerned that it would be perceived as them not being able to care for their own. However, because most of them were migrants they were cut off from the support networks and social connections that would have been available for them in their home countries. One participant described his awareness of the impact his impairment has had on his wife:

‘I used to work and we had a comfortable life. Now, I have to rely on my wife. She has to go to work and make sure there is food in the house for me. I try to help, try to clean the floor but I can’t even see whether the floor is clean. I am such a burden to her’ (Participant, p150).

Participants valued the availability of culturally specific services, while those not being provided with them noted the lack, for example, of the food they liked and were used to.

Participants living in care homes felt particularly isolated, unhappy and vulnerable.

Considerations: The sample size is relatively small. Nearly all participants are of immigrant backgrounds and living in places where support services provided by Chinese welfare organisations are available. The results are therefore not likely to be representative of experiences of those who were born in the UK, and also of those who live in rural areas, which have limited access to Chinese welfare organisations.

Declaration of interest: SCIE hosts ‘Think Local Act Personal’ (TLAP), the organisation that produced the videos.

Evidence statements

The evidence statements were guided using the 6 ‘scoping framework’ (refer to the review background document for GC5) higher order categories:

- Respect, dignity and control
- Personalised support

- Information and communication
- Active participation in lived experience of care
- Continuity of care and transitions (including access to care)
- Care and support for people's needs.

These themes are represented within the evidence statements that follow. The statements do not speak to individual themes; the statements often reflect several of the themes. Each statement is prefixed with the letter 'V' (which stands for Views studies) and a number, which is the statement's numerical order in the list. Evidence statements prefixed with a letter 'U' were developed as a result of additional searching of literature or suggestions made by Guideline committee members.

All evidence statements that follow are based on studies that are rich in direct user views.

Evidence statement measures

The evidence statements report two measures: amount and quality. The following conventions were used for amount of evidence:

- 1 to 2 studies - 'small amount'
- 3 to 4 studies - 'some evidence'
- 5 - 'moderate amount'
- 6 and above - 'good amount'.

In terms of quality, if more than 1 paper was used in an evidence statement, an average was taken of the weights assigned for each paper in order to provide an overall measure of quality for the evidence statement. For example, in a statement with 3 papers, if the first were rated medium (+), the second high (++) and the third low (-), the evidence statement would be recorded as 'medium' level quality. If 2 papers were scored high (++) and 1 medium (+), the evidence statement would be recorded as 'high' level quality. If there were an even number of studies of two quality levels (for example, two high and two medium), the evidence statement would be weighted on the lower side and recorded as 'medium' level quality.

Evidence statements from review of literature on views and experiences

V1	**Matching service users and care staff** This evidence statement is based on 1 study of medium level quality (Valdeep et al. 2014 +), which examined satisfaction with social care services among black and minority ethnic populations. The study found that matching (for example, on ethnicity, age and gender) was not perceived as essential to service users, who prioritise personalised care and being listened to.
V2	**Consistency of care** This evidence statement is based on some evidence of overall medium level quality. In the first of 4 studies (Cameron et al. 2016 ++) tracked a group of homeless women and women at risk of homelessness to determine how their service needs (including social care needs) changed over this time. The second study (Katz et al. 2011 +) examined the views of what older people with high support needs value in their lives, and within services. The third study (Goodman et al. 2013 +) aimed to explore how older people with dementia discussed their priorities and preferences for end-of-life care. The fourth study (Cook et al. 2006 +) aimed to draw on older people's narratives to illuminate the experience of living in a care home. The studies found that consistency of care delivery is important to adults who receive home help and improves relationships between carers and their clients, which impacts positively on quality of care.
V3	**Home help provision** This evidence statement is based on some evidence of overall medium level quality. In the first of 4 studies (Valdeep et al. 2014 +) examined satisfaction with social care services among black and minority ethnic populations. The second study (Barnes and Mercer 2006 ++), discussed users' experiences using mainstream, community-based support services and how this contrasted with disabled people's experiences of user-led services. The third study (Katz et al. 2011 +) examined the views of what older people with high support needs value in their lives, and within services. The fourth study (Cook et al. 2015 ++) aimed to help older people to tell their stories of life in a care home. The studies found that tension in home help provision between what is expected and what can be reasonably delivered can affect the perception of care quality being received.
V4	**Supporting independence** This evidence statement is based on a good amount of evidence of overall medium level quality. The first of 9 studies (Trappes-Lomax and Hawton 2012 ++), explored the voices of older people describing their experiences of what service users thought worked well or could work better about rehabilitative care. The second study (Hillcoat-Nallétamby 2014 +), aimed to address the knowledge gap in research about older people's own understandings of independence. The third study (Katz et al. 2011 +) examined the views of what older people with high support needs value in their lives, and within services. The fourth study (Cook et al. 2015 ++) aimed to help older people to tell their stories of life in a care home. The fifth study (Goodman et al. 2013 +) aimed to explore how older people with dementia discussed their priorities and preferences for end-of-life care. The sixth study (Hamilton et al. 2016 ++) aimed to explore how, within mental health services, people's engagement with personal budgets may have impacted on their sense of empowerment and their relationships with services. The seventh study (Swain 2005 +) aimed to conduct a review of and support the development of service user involvement at all levels and

	within all areas of Leonard Cheshire activity. The eighth study (Abbott et al. 2000 +) aimed to explore the range and diversity of views held by older people living in sheltered housing and residential care settings about independence and involvement. The ninth study (Stewart et al. 2011 +) aimed to examine the experiences of 8 housebound, community-living older people of post falls. The studies found that despite growing dependency, care users often express the desire to do things for themselves for if possible. Therefore, service delivery needs to respect people's desire for independence and plan around it.
V5	**Personal budgets and direct care payments** This evidence statement is based on some evidence of overall medium level quality. In the first of 4 studies (Irvine et al. (2016 +) aimed to examine the factors affecting the social care experiences of physically disabled people from Chinese backgrounds in England. The second study (Hatton et al. 2011−) aimed to capture experiences of using personal budgets from personal budget holders and for carers of personal budget holders. The third study (Barnes and Mercer 2006 ++) discussed users' experiences using mainstream, community-based support services and how this contrasted with disabled people's experiences of user-led services. The fourth study (Hamilton et al. 2016 ++) aimed to explore how, within mental health services, people's engagement with personal budgets may have impacted on their sense of empowerment and their relationships with services. The studies found that personal budgets and direct care payments are overly complicated and applying for them and using them is cumbersome.
V6	**Cultural and personal values** This evidence statement is based on a small amount of evidence of overall medium level quality. The first study (Irvine et al. 2016 +) aimed to examine the factors affecting the social care experiences of physically disabled people from Chinese backgrounds in England. The second study (Rainbow Ripples and Butler 2006 ++) aimed to explore the way services are provided to lesbian, gay and bisexual disabled people in Leeds. The studies found that cultural and personal values need to be respected when delivering care and used to tailor care to meet the specific needs of individuals.
V7	**Person-centred care** This evidence statement is based on a good amount of evidence of overall medium level quality in relation to views on person-centred care. In the first of 6 studies, (Rainbow Ripples and Butler 2006 ++) aimed to explore the way services are provided to lesbian, gay and bisexual disabled people in Leeds. The second study (Barnes and Mercer 2006 ++) discussed users' experiences using mainstream, community-based support services and how this contrasts with disabled people's experiences of user-led services. The third study (Katz et al. 2011 +) examined the views of what older people with high-support needs value in their lives, and within services. The fourth study (Swain 2005 +) aimed to conduct a review of and support the development of service user involvement at all levels and within all areas of Leonard Cheshire activity. The fifth study (Beech et al. 2013 ++) aimed to examine the integration of services provided at the patient/practitioner interface. The sixth study (Wilson et al. 2009 +) aimed to consider how relationships in care homes influence the experience of older people, their families and staff. The studies found that person-centred

	care is perceived more positively, especially for disabled people (including those with sensory impairments).
V8	**Key workers** This evidence statement is based on some evidence of overall medium level quality. In the first study, (Cameron et al. 2016 ++) tracked a group of homeless women and women at risk of homelessness to determine how their service needs (including social care needs) changed over this time. The second study (French and Swain 2006 +) aimed to gather some 'real world' experiences to illustrate some of the qualities users value in occupational therapists and some of the problems, which may occur in therapy from the user's viewpoint. The third study (Swain 2005 +) aimed to conduct a review of and support the development of service user involvement at all levels and within all areas of Leonard Cheshire activity. The studies found that where services are fragmented, and affect service quality, (especially for adults without a fixed address), a good key worker to liaise between services could make delivery of care seamless.
V9	**Information about services** This evidence statement is based on a good amount of evidence of overall medium level quality. In the first of 8 studies, (Barnes and Mercer 2006 ++) discussed users' experiences of using mainstream, community-based support services and how this contrasts with disabled people's experiences of user-led services. The second study (Cameron et al. 2016 +) tracked a group of homeless women/women at risk of homelessness to determine how their service needs (including social care needs) changed over this time. The third study (Katz et al. 2011 +) examined the views of what older people with high support needs value in their lives, and within services. The fourth study (Abbott et al. 2000 +) explored the views and experiences of adults living in sheltered housing or residential care settings. The fifth study (Stewart et al. 2011 +) examined older people's experiences of living with falls at home. The sixth study (Beech et al. 2013 ++) examined care received before, during and after a health crisis. In the seventh study, (Peace et al. 2016 +) explored preferences for where and with what kinds of support older people with vision impairments would like to live. The eighth study (Ward and Banks 2017 +) study looked at the views and experiences of older people in residential care homes who have experienced sight loss. The studies found that information about services is lacking, inaccessible, sub-standard or inconsistent, especially when accessing follow-on care. This is a problem for people with newly acquired impairments or multiple sensory impairments.
U3RQ1-3	**Needs of lesbian, gay and bisexual people** This evidence statement is based on some evidence of overall medium level quality. The first of 3 studies, (Willis P et al. 2016 +) was about lesbian, gay and bisexual (LGB) people who are prospective users of residential and nursing homes. The second study (Westwood 2016 −) explored prospective social care choices among LGB people. The third study (Rainbow Ripples and Butler 2006 ++) aimed to explore the way services are provided to LGB disabled people in Leeds. The studies found that services should be sensitive to the specific needs of LGB people and understand the discrimination they face.
U4RQ1-3	**Culturally sensitive food** This evidence statement is based on a small amount of evidence of overall medium level quality. In the first of 2 studies, (Blake et al. 2016 ++) examined the causes for consistently low levels of satisfaction with social

	care services among Bangladeshi and Pakistani service users in England in existing surveys. The second study (Irvine et al. 2016 +) aimed to examine the factors affecting the social care experiences of physically disabled people from Chinese backgrounds in England. The studies found that services should provide culturally sensitive food to users.
U5RQ1-3	**Lesbian, gay, bisexual, transgender, and queer and intersex individuals' identity** This evidence statement is based on a small amount of evidence of overall low level quality. In the first of 2 studies, (Westwood 2016 −), explored prospective social care choices among LGB people. The second study (Willis P et al. 2016 +) examined the views of prospective lesbian, gay and bisexual (LGB) service users about how they anticipated good care should look if they were to move into residential care. The studies found that LGBTQ individuals ‘continue to live in fear and hide their identities' in care spaces.
U6RQ1-3	**Opportunities for people with learning disabilities** This evidence statement is based on some evidence, including videos, of overall low level quality. The first study (Gajeswka and Richard 2016 +) examined the views of people with intellectual disabilities of the benefits of attending day and community learning centres. The first video from TLAP (2010 −) was about a service user who is profoundly deaf, and described how he lost confidence when aged 16 and started using his personal budget to help with his care. The second video from SCIE (2009 −) demonstrated the benefits of giving people control over their personal budget. The study and videos found that providing people with learning disabilities access to opportunities, such as day centres and personal budgets, helps to increase their confidence and abilities.

Included studies for these review questions

Barnes C and Mercer G (2006) Creating user-led disability services in a disabling society. Bristol: Policy Press

Cameron A, Abrahams H, Morgan K et al. (2016) From pillar to post: homeless women's experiences of social care. Health & Social Care in the Community 24(3), 345–52

Goodman C, Amador S, Elmore N et al. (2013) Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes. International journal of nursing studies 50, 1639–47

Hamilton S, Tew J, Szymczynska P et al. (2016) Power, Choice and Control: How Do Personal Budgets Affect the Experiences of People with Mental Health Problems and Their Relationships with Social Workers and Other Practitioners?. British Journal of Social Work, 719–36

Hatton C and Waters J (2011) The National Personal Budget Survey: June 2011. London: Think Local Act Personal

Hillcoat-Nallétamby S (2014) The meaning of "independence" for older people in different residential settings. The Journals of Gerontology: Series B: Psychological Sciences and Social Sciences 69B, 419–30

Irvine F, Yeung EYW, Partridge M et al. (2016) The impact of personalisation on people from Chinese backgrounds: qualitative accounts of social care experience. Health & Social Care in the Community, Advance online publication. doi: 10.1111/hsc.12374

Katz J, Holland C, Peace S et al. (2011) A Better Life: What older people with high support needs value. York: Joseph Rowntree Foundation

Rainbow Ripples and Butler R (2006) The Rainbow Ripples report: lesbian, gay and bisexual disabled people's experiences of service provision in Leeds. Leeds: Rainbow Ripples

Swain J (2005) Independent Evaluation: Developing User Involvement in Leonard Cheshire. Final Report. Newcastle: Northumbria University

Trappes-Lomax T and Hawton A (2012) The user voice: older people's experiences of reablement and rehabilitation. Journal of Integrated Care 20, 181–94

Valdeep G, Husain F, Vowden K (2014) Satisfaction with social care services among Black and Minority ethnic populations: exploring satisfaction with adult social care services amongst Pakistani, Bangladeshi and white British people. London: National Centre for Social Research

Westwood S (2016) 'We see it as being heterosexualised, being put into a care home': gender, sexuality and housing/care preferences among older LGB individuals in the UK. Health & Social Care in the Community 24, e155–e163

Willis P, Maegusuku-Hewett T, Raithby M et al. (2016) Swimming upstream: the provision of inclusive care to older lesbian, gay and bisexual (LGB) adults in residential and nursing environments in Wales. Ageing and Society 36, 282–306

Willis R, Khambhaita P, Pathak P et al. (2016b) Satisfaction with social care services among South Asian and White British older people: the need to understand the system. Ageing and Society 36, 1364–87

Yeung EYW, Partridge M, Irvine F (2016) Satisfaction with social care: the experiences of people from Chinese backgrounds with physical disabilities. Health & Social Care in the Community 24, e144–e154

3.2 Views and experiences of barriers and facilitators to good care

Introduction to the review question

Review questions 2 and 3 aimed to explore the views and experiences of adults in terms of what barriers and facilitators to good care people identified within the context of the four main settings that were prioritised for this review: hospital, community, own home and residential care. The barriers to good care in residential care homes were a group chosen by the Guideline Committee for additional analysis and are presented in section 3.3.

Review questions

2. For people who use adult social care services, what are the barriers related to improving their experience of care?

3. For people who use adult social care services, what would help improve their experience of care?

Summary of the review protocol

Review questions 2 and 3

These review questions sought to identify evidence on:

- Barriers to improving the experience of adult social care services, including barriers to people being engaged in their care planning and delivery; lack of information about what services users value or need; evidence about the characteristics of services where improvements in user experience are either not evaluated, or not improved following negative evaluation.

- Facilitators to improving the experience of adult social care services, including use of different kinds of information about service users' needs or views to inform development; engagement with formal groups or advocates, and so on. These questions therefore sought to identify qualitative, quantitative or mixed-methods studies including:
  - process evaluation studies where barriers or facilitators are assessed
  - qualitative assessments
  - mixed-methods studies
  - systematic reviews of the above.

Population

Adults aged 18 or over who use social care services

Intervention

Experience of social care services

Setting

All UK settings where care is delivered

Outcomes: Qualitative themes – relevant to review questions 2 and 3

1. Wellbeing and quality of life (related to health, mental health and social wellbeing).
2. Engagement with services and care, including understanding relevant care and management issues where appropriate.
3. Choice and control.
4. Satisfaction of people who use services (including carer, family and advocate perceptions of how satisfied the people who use services are).
5. Perceived and objectively measured independence.
6. Ability to carry out activities of daily living with or without support.
7. Continuity of care.
8. Participation in social and community activities, including training and education, paid and unpaid employment.
9. Resource use.

10. Security and personal safety.

How the literature was searched

Electronic databases in the research fields of social care, health, and social sciences were searched using a range of controlled indexing and free-text search terms combining the four concepts of:

- Views and experiences – including: views, experience, preference, perspective, satisfaction, dissatisfaction, feedback, learn, attitudes, expectation, complaint
- Setting (social care services) – including: social care, social provision, social service, community, residential, home, personal budget, direct payment, care plan
- Population (adults) – including: adults, older people, frail, elderly, homeless, disabled, disability
- Study type and outcomes – including: quality studies, evaluation studies, measures or outcomes, economic studies.

The search was restricted to human studies in the English language and published from 2000. A cut-off year of 2000 was chosen to include those studies that were most likely to be generalisable to the England and Wales policy and legislative context, and to manage the volume of evidence. Two significant policy and legislative changes at this time were the Health and Social Care Act 2001 and Valuing People 2001 that were intended to change the way people experienced health and social care services.

The search aimed to capture both journal articles and other publications of empirical research. Additional searches of websites of relevant organisations, and of research archives or databases, were undertaken to capture literature that might not have been found from the database searches.

Economic evidence was searched for as part of the single search strategy, and included searching within the economic databases such as the NHS Economic Evaluation Database (NHS EED) and the Health Economic Evaluations Database (HEED).

A call for evidence from stakeholders, providing an opportunity for any groups or organisations to submit relevant evidence, was also carried out at the beginning of the review.

Guideline committee members were also asked to alert the NICE Collaborating Centre for Social Care to any additional evidence, published, unpublished or in press, that met the inclusion criteria throughout the review.

The database and website searches were undertaken in March 2016. Update searching of the bibliographic databases searches took place in January 2017. When the update searches were run, an adjustment was made to the original search strategy to include the term ‘disabled’ in the population segment of the search.

See Appendix A for full details of the search.

How studies were selected

Search outputs (title and abstract and only) were stored in EPPI Reviewer 4 – a software program developed for systematic review of large search outputs – and screened against the inclusion and exclusion criteria defined in the scope, which were as follows:

- Exclude on language. Not published in English.
- Exclude on date. Studies published prior to 2000 will be excluded. Systematic reviews where fewer than 80% or more of included papers meet our inclusion criteria – this includes publication date.
- Exclude on country. This study is not set in the UK.
- Exclude on population 1. Participants are less than 18 years of age.
- Exclude on population 2. Study is with carers (unless they are being used to give proxy views on behalf of people who use services).
- Exclude on intervention. For RQ1–3: Not about user views of services – what is valued, or barriers or facilitators to using services.
- Exclude on setting. Not in one of the settings where adult social care is delivered as specified in the protocol.
- Exclude on outcomes. Not about views and experiences of services
- Exclude on evidence type. For example, opinion pieces.

There were 1,611 studies that met the initial inclusion criteria and were included based on the title and abstract. Studies were then mapped against the criteria outlined at the beginning of Section 3 and sampled accordingly. Full texts of included studies were retrieved and screened against the inclusion criteria.

Full texts were retrieved and screened against the inclusion criteria. Fifteen studies were identified that were relevant to the question on barriers and facilitators to good care. There was some overlap with review question 1 on views and experiences. Four studies were identified that could answer RQ1 on views and experiences and also RQ2 on barriers to good care, 8 studies were relevant to both RQ1 and facilitators, 3 studies were relevant to all three questions on views and experiences and barriers and facilitators, and 1 study was about barriers only. All studies on barriers and facilitators are presented in this section.

See Appendix B for full critical appraisal and findings tables.

Narrative summary of the evidence

Abbott S, Fisk M, Forward L (2000) Social and democratic participation in residential settings for older people: realities and aspirations.

Methods: Small-scale qualitative study.

Data: Views and experiences of living in sheltered housing and residential care homes: Qualitative interviews.

Country: NW England, W Midlands and Wales.

Question area(s): Q3 Facilitators to care (and Q1 Views and Experiences)

Setting: Residential care and ‘extra care housing’.

Framework areas: Respect, dignity and control; care and support for people’s needs.

This report presents analysis of data from an overall medium (+) level qualitative study aiming to explore the range and diversity of views held by older people living in sheltered housing and residential care settings about independence and involvement.

Sample size: 122 interviews were carried out with residents of sheltered housing and residential care homes.

Analysis: Data were initially analysed using thematic content analysis. After initial identification and categorisation of themes, more detailed analysis was applied to minority views. Dissenting views were divided into two categories: dissatisfaction with what the authors call ‘local matters’ (for example, the standard of cooking, the choice of social events, and the personality of the staff) which they excluded from this paper. Other views expressing dissatisfaction with the processes and structures, which reflected the residential setting, were included in the paper.

Findings

Page 331: The authors comment that dissatisfaction views were in the minority and that ‘most residents interviewed were very appreciative of their surroundings, and did not express dissatisfaction with levels of participation where they lived’ (Authors).

Page 334: The authors discuss that an important impact of moving into residential care for some people is the loss of paid work and running of their own homes. Some participants spoke of developing strategies for overcoming loss of independence. The authors report that:

‘A significant minority of residents spoke of a variety of practical ways in which they participated in the running of the house. It was important to be able to offer help (for example, laying the table at lunch-time, helping with the washing-up, gardening, etc.), and suggested that these activities increased their self-esteem’ (Authors). ‘The house-keeper’s husband went into hospital suddenly and she was going to call someone to get the tea. But I said that I’d do it…, and felt quite proud to be involved’ (Woman participant, aged 76, p334).

Page 334: The authors go on to say that:

‘Staff had recognised the value of practical participation and in several houses there was a rota for laying the table: “to make them feel involved”’ (staff).

Page 336: The authors state that residents had positive aspirations: ‘to be involved more strategically in the running of the residence’ (Authors).

However, the authors mention that information issues were a problem. One resident said:

‘They put things on the notice board but I can’t read it…I have to rely on someone telling me…people don’t always think to tell me’ (Woman participant, aged 85, p338).

And that:

‘There was substantial evidence of limited choice (particularly concerning meals), an absence of clear processes for redress, and limited opportunities for representation’ (p338).

Page 336: The authors note that none of the care homes had a formal complaints procedure in place. Most staff expected complaints would be dealt with by informal discussion. One care home did, however, have a formal committee that met with residents twice yearly, specifically to deal with complaints. Residents, however, expressed mixed feelings about these committees; while some residents felt making suggestions to these committees was ineffective, for example:

‘The Committee took little notice of what residents wanted and did not consult them enough’ (Woman participant, aged 90, p335).

And: ‘You might make suggestions but nothing will happen, so you stop suggesting things’ (Woman participant, aged 95, p335).

Others wanted to be better informed about them:

‘They have a committee that meet on Thursday. We are never told what goes on. They just say, “If there’s anything special…” I think we ought to know what goes on – even if it’s just to make your brain work. We haven’t a clue…’ (Woman participant, aged 85, p366).

Some other residents sought representation on committees but found a barrier to doing so:

‘I would like to participate more. We could have a representative on the Committee – but the Committee didn’t respond to this’ (Woman participant, aged 86, p336).

However for others, the Committees were spoken of more positively, for example:

‘The meetings are useful, and we can discuss outings, classes, shopping…’ (Woman participant, aged 87, p336).

The authors comment that although for some, representation on committees ‘may be little more than a token gesture in reality’ (p337), they do demonstrate an ‘acknowledgement of the possibility of some degree of power-sharing’.

The conclusion reached by the authors was that: ‘problems have to be owned before solutions can be found and implemented’ and that ‘a necessary although not sufficient first step in achieving a more participative culture is for organisations and individuals providing sheltered housing or residential care to learn how to encourage and attend to dissenting as well as majority voices among their residents’ (Authors, p338).

Considerations: Although the study seeks to explore a range of views, none of the study questions ask directly about service use – the views material comes from the authors asking about participants’ involvement in their own lives within these settings. Ethical considerations are not reported in the paper so there is no way of knowing if these were considered or not. The sample of research sites was opportunistic, and was identified in discussion with service providers in the North West of England, the West Midlands, and Wales. Quota samples within the residential settings were used – set with the intention that a third of respondents should be aged between 70 and 84 and that a quarter of respondents should be men – but only the first of these criteria was achieved. Although efforts were made to recruit and engage with minority ethnic residents and those ‘residents who might be less likely to volunteer (less outgoing personalities, those with hearing impairments)’, the sampling was opportunistic and therefore may not be representative of other adults in these settings.

Beech R, Henderson C, Ashby S et al. (2013) Does integrated governance lead to integrated patient care? Findings from the innovation forum.

Methods: Small-scale qualitative study using a case study design.

Data: Patient interviews (46) covering care received before, during and after a health crisis.

Country: England.

Question area(s): Q2 Barriers to care, Q3 Facilitators to care (and Q1 Views and Experiences).

Setting: Across and within organisational (health and social care) boundaries.

Framework areas: Respect, dignity and control; continuity of care (including access); care and support for people's needs.

This report presents analysis of data from an overall high (++) level qualitative study aiming to examine the integration of services provided at the patient–practitioner interface, and in particular the degree to which the actions of frontline staff working within and across organisations supported the efforts to reduce the use of emergency hospital bed days by older people. A secondary aim of the research was to assess how closer inter-organisational integration was affecting the delivery of services at the patient–practitioner interface.

Sample size: 18 patients (six in each site) regarded as eligible for care 'closer to home' services, at the point of and following a health crisis, and with one of three conditions [Chronic Obstructive Pulmonary Disease (COPD), stroke or falls].

Analysis: Tape-recorded interviews were transcribed and participant details were anonymised. Themes were identified, and categories developed and refined inductively, through the constant comparative method of grounded theory (Glaser and Strauss 1967). The researcher responsible for each site independently coded the data for their site line by line. Data and ideas were shared through a series of meetings and the joint coding-framework was agreed. Common and divergent themes to all sites were discussed, compared and developed during the analysis. Emergent findings were also informed by other data such as interviews with senior managers and documentary analysis. Themes that were significant in the data from all three sites remained in the final analytical framework.

Findings

The care delivery experiences of patients are grouped into the three key phases of their journeys: pre-crisis, crisis, and rehabilitation (including discharge from acute care).

Summarising across the narrative accounts, in terms of barriers and facilitators:

1. The pre-crisis phase: Although some people had been quite well before their health crisis, many had suffered significant periods of ill health. In particular, people who had fallen and people with breathing problems gave examples of having delayed help seeking or reporting accidents, being reluctant to ‘bother’ professionals (in particular GPs). Delayed or no contact with primary and community care services had implications for crisis prevention. The study cites that 14 out of 18 people said that they had suffered a previous fall, but in many cases had not reported these to health professionals (Authors, p600). Blockages to connecting ‘closer to home’ services to people could be a result of the way mainstream primary and community services were organised. Staff members said that GPs had a key role in offering care during the pre-crisis and crisis phases, but they thought that changes to the GP appointment system had created barriers. Some staff praised out-of-hours rapid response teams for being typically faster to respond than out-of-hours GP services (Staff, p600).

2. The crisis phase: It has been projected that up to half of those people who fall and are seen by the ambulance service do not need hospital admission (Snooks et al. 2006). This research found that very few people were diverted at the point of making an emergency call. Mrs N’s patient journey not only highlights an uncommon example of a successful ‘diversion’ by paramedics from acute care, but also describes her feelings about a perceived poor service from her primary care provider:

'If I press that [alarm], then it answers in the hall there. That’s how I got the paramedics you see, because – not being unkind – you can be on the phone for hours trying to ring a doctor and you don’t get anywhere. So I ring now for the paramedics’ (Female participant, p601).

The call centre contacted the emergency services and the paramedics decided that hospital could be averted: instead referring her to an intermediate care service.

Two patients, one male and one female, spoke of episodes in which they were treated in A&E for fractures and discharged home without suitable arrangements for follow-up care and support. In both cases, family members intervened and contacted community services to arrange this. (Authors, page 601). The male patient's daughter arranged for home care from his social services department, which then referred him on to community rehabilitation, and the female patient learned about adult care services from a family member. Her GP subsequently referred her to the intermediate care team. The patient journeys highlighted the important role that family and friends play in providing follow-up care. One issue identified by staff working for care ‘closer to home’ services in all the sites, was that current referral patterns meant that opportunities were being missed to prevent ‘avoidable’ acute bed use. A key problem was the lack of knowledge of the existence and function of these services by potential referrers (Authors, p601).

3. The rehabilitation phase: Many patients and carers were concerned with the quality of acute hospital discharge planning, especially their lack of involvement in this. Two frail patients from different sites with chronic obstructive pulmonary disease experienced unsuccessful discharges and thought that this was because they were not feeling well enough to go home (Two women participants in their 80s, p602). One of them commented:

‘I was astonished when the young doctor said “I think you can go home tomorrow”. I said “I don’t feel fit. … What about me going to the [rehabilitation unit] for a bit?” And he said “Oh no, you’d be much better at home, get back to normal”. And so it was against my will. I suppose they would say I finally agreed, but there didn’t seem any option but to go home – and it was then I found I wasn’t able to cope. … With hindsight, I was a bit weak to go with it, but I was so weak’ (Female patient, p602).

Other patients who needed extended periods of rehabilitation faced delays in access to bedded rehabilitation with the choice of discharge destination seemingly driven by the availability of community hospital and intermediate care beds (Authors, p602). On the other hand, in some cases, decision-making about ongoing care following an acute attendance or admission resulted in timely transfer and patients were satisfied. For example, one patient was screened in the hospital’s observation ward by intermediate care staff, offered a 6-week package of intensive physiotherapy and transferred to the rehabilitation unit the next day (Authors, p602). Many of the patients who received ongoing care from rehabilitation services commented on the personalised nature of care provided within a holistic and integrated approach (Authors, p602).

The authors conclude that there were some issues common across all the phases above. Services for preventing health crises were underused because people were slow to access care following accidents or when feeling unwell and because health professionals failed to inform patients about preventative services such as falls prevention services. At the time of a health crisis, there was a reliance on 'traditional' referral patterns and services, partly due to a lack of knowledge about care 'closer to home' services among key frontline professions and because out-of-hours rapid response services were not always available. Patients spoke about a lack of information and signposting about services that they could themselves use before, during or after a health crisis. Communication between professionals, particularly across organisational boundaries, was a challenge. Patients described having to undergo multiple assessments. Information sharing was impeded by a lack of compatible technologies.

Considerations: The methodology, including how the sample was recruited, data collection and analysis, have been reported explicitly. The only limitation is the absence of reporting of the study design. The authors said the methods used are reported in more detail elsewhere (Henderson et al. 2011).

Blake M, Bowes A, Valdeep G et al. (2016) A collaborative exploration of the reasons for lower satisfaction with services among Bangladeshi and Pakistani social care users.

Review Question: 1 and 2.

Methods: In-depth interviews with social care users.

Data: Experiences of receiving care from the perspectives of service users and their families.

Country: England.

Setting: Own home.

Scoping framework areas: Personalised support; information and communication; continuity of care and transitions; care and support for people's needs.

Population group: Black and minority ethnic.

This paper rated high (++) quality discusses the findings from a study which examines the causes for consistently low levels of satisfaction with social care services among Bangladeshi and Pakistani service users in England in existing surveys (The NHS Information Centre, Social Care Team 2012; HSCIC, 2013) compared with white British users. The research had three stages:

- Cognitive interviews, which examine whether user surveys measure satisfaction consistently
- Service user and families' views about receiving care and perspectives on providing care as expressed by social workers, provider agencies and care workers
- Collaborative workshops to validate the findings and involving service users and staff.

The main focus of this paper is the service user views about receiving care.

Sample size: A purposive sampling approach was used to select the study location and research participants. A comparison is made between the 44 Asian service users and 19 white British service users in terms of how they understood and responded to survey questions, in order to ascertain whether this could be connected to the lower satisfaction level with adult social as described by black and minority ethnic communities. There were also comparisons between the perceptions of the 63 service users and the 24 social care practitioners.

Analysis: A thematic analysis was carried out where 'the coded data were interrogated with a view to maintaining a balance between the subjective and objective (Moustakas 1994)'. This meant that while the validity of the accounts of lived experiences of social care users were paramount and held subjective value, these were compared and contrasted with the accounts of service providers in order to understand 'the prejudices, viewpoints or assumptions regarding the phenomenon under investigation (Katz 1987 as cited in Patton 2002)' (Authors, p4).

Findings

Care pathways common to all groups: Three aspects played a key role in perceived satisfaction with care: accessing care through the local authority; interaction and communications with social workers; and receiving care from care and support workers. There were common drivers of satisfaction for all three ethnic groups.

Accessing care

Ease of making contact with social workers, the speed of undertaking an assessment and the care package agreed was fundamental to user satisfaction for all three ethnic groups:

'Those that don't ask don't get anything' (Female service user, Pakistani origin, Leeds, p5).

With the exception of services to address unmet needs (such as loneliness and isolation), care gaps were identified in the shape of more equipment and more time from care and support workers.

Communication with social workers

Reliability and consistency were two main concerns in relation to communication. Reliability included social workers keeping appointments and being responsive. Not having an assigned social worker was also identified:

'We have to contact the social services team in the area to get hold of the actual social worker' (Relative of male service user, Bangladeshi origin, Birmingham, p5).

Receiving care

The nature of care was the most important driver of satisfaction. Service users expressed satisfaction where staff had gone out of their way to provide a service.

A lack of time caused dissatisfaction for both service users and carers:

‘...one is punctuality, two is the rapport and three is getting the work done properly. She’s [my care worker] got all three. If you haven’t got all three, then it might be a problem’ (Service user, man, white British, London, p6).

Satisfaction, ethnicity and culture: Common issues led to satisfaction or dissatisfaction among all three population groups. But there were cultural and ethnic differences. Cultural issues were interpreted and expressed differently by service users, by their families (including carers) and by local authorities or providers.

They ‘take care of their own’

Service providers assumed that Asian families would prefer to 'take care of their own', consequently making them less aware of their entitlement to services and less likely to seek help, or only do so at crisis point.

Family and caring

Caring was often a female role supplemented with a small amount of care from the local authority. Where there were language or literacy issues, care providers sometimes could not communicate directly with the women who were the main carers about what the service user's needs were. The authors note that:

‘Disentangling reasons for dissatisfaction is difficult where the wider family is involved – care users, their main carers and those who act as communicators with the care system’ (Authors, p7).

Language and communication barriers

Accessing care, especially through local authority automated phone lines, was problematic for Bangladeshi and Pakistani people. In the absence of language services (interpreter or own language staff), communications with social workers was hampered, care packages could not be negotiated properly, and explaining tasks and building rapport with care workers was problematic.

Ethnic matching as a response to cultural and religious difference

Service users identified key dimensions of ethnic matching including a shared language, preparation of culturally appropriate food, the gender of care workers, religion (for support with ritual ablution for prayer), and a general cultural understanding to help build rapport and familiarity. Significantly, care user–care provider ethnic matching was not always an essential part of improving satisfaction. For example, white British care workers were perceived to perform practical tasks such as cleaning and changing clothes more effectively than care workers of other ethnicities.

Meeting service user needs

From the provider and local authority perspectives ethnic matching was not always possible so compromises had to be made, for example matching South Asian origin but not language. This contrasted with the view that cultural familiarity could weaken the fundamentally professional (and formal) nature of the care user–care worker relationship. For example, a senior manager (homecare provider) explained that service users may say:

'I want someone from my community because she speaks my language. I like it – somebody comes in, in the day and I can speak my language' or, 'I confide in her'. Or 'It's like a daughter coming to the door'. Whereas another service user will turn round and say, 'It's my private life. I don't want somebody to come in and intrude and ask me all questions about – where's your daughter?' (Senior manager, homecare provider, p8).

Care workers were not receiving cultural awareness training, although some were still showing cultural sensitivity, which contributed positively to satisfaction.

Collaborative workshops generated a number of suggestions from service users:

- Use local media and community organisations to raise awareness of services and reduce stigma.
- Good communication between local authorities and care providers about service users' individual needs so as to develop person-centred care packages.
- Service users to be assisted to provide and update a file about their needs.
- The support needs of carers within the family (usually women) to be considered.
- Improved communication with non-English speakers, for example with appropriately trained interpreters, and more face-to-face contact.

- Recruit a local care workforce that mirrors the diversity of the service user population.
- Training in cultural awareness for social care practitioners (Authors, p8).

Considerations: The use of practitioner interviewees allowed for explanations to be provided for some of the causes of dissatisfaction, for example inadequate resources and lack of training. It also allowed for collaborative working between service users and practitioners in developing solutions. The wider context for the study, black and minority ethnic adult social care service user dissatisfaction, is clearly explained. However, the settings where the interviews informing this study took place are not described. This is worth noting, since it is part of the context for the interviews and could influence how participants feel about being interviewed and what they are willing to state in the interview itself.

Colston G (2013) Perspectives on personal outcomes of early stage support for people with dementia and their carers.

Methods: Small-scale qualitative study.

Data: Experience of using the early stage support service and what it means to the individuals in the early stage of dementia. Semi-structured interviews with people recently diagnosed with dementia.

Country: Scotland.

Question area(s): Q3 Facilitators to care (and Q1 Views and Experiences).

Setting: Post diagnostic support service.

Framework areas: Active participation in lived experience of care.

This research of low (−) quality seeks to identify the personal outcomes of early stage support provided by Alzheimer's Scotland Dundee Early Stage Support Service by conducting semi-structured interviews with individuals living with a diagnosis of dementia who are using the service, as well as their carers and the staff and volunteers who provide the support. The narrative below is from the interviews with people with dementia.

Sample size: A purposive sampling strategy was used to identify 5 participants, all Men and with dementia aged 63 to 76 who have recently been diagnosed with dementia, living in the community and accessing the post diagnostic support service. One man had been using the service for four years, 3 men for one year and one man for 18 months.

Analysis: Data was analysed using the Five Pillars of Post Diagnostic Support: Peer support; community connections; understanding the illness; planning for the future-decision making; planning for the future – future care to understand what elements of the Five Pillars appeared to be the most important to people living with a diagnosis of dementia, as well as to carers. The narrative was analysed using the Talking Points Personal Outcomes Approach, categorising responses that are valued by users (Cook and Miller Joint Improvement Team 2012, p4). The researcher was also a practitioner and knew most of the participants through their use of the Resource Centre. This relationship, it was claimed, helped with the delivery of the research, as (the researcher) had an understanding of dementia.

Findings

Key findings:

The Five Pillars have been adopted as part of Scotland's National Dementia Strategy and resulted in the Scottish Government making a commitment to ensure that everyone given a diagnosis of dementia is entitled to a year's post diagnostic support. The experiential perspective of individuals was analysed within these pillars: peer support; community connections; understanding the illness; planning for the future-decision making; planning for the future – future care.

Peer support and community connections were the key pillars of support that people with dementia highlight as significant. A male participant (1) uses the service as a continuation of activities he has enjoyed all his life and as a way to meet with others he gets on well with (Author).

'Meet other people the same as me, the staff help as well' (Male participant 2, p5).

'Out and about meeting different people that was something, rather than sitting here all day. Meeting other people is the best part of it.... Otherwise it would be a long week looking out the window' (Male participant 3, p5).

All the respondents talked about the importance of community connections as described in the following quotes:

'Along came Football Memories – right down my street, always loved football… I had lost my love of football when I was diagnosed; there was nothing in it for me. Football memories encouraged me to go back to football' (Male participant 4, p6).

'Dementia Resource Centre – very, very normal, I'm in a situation where I am happy. It (the service) keeps me in touch with the real word. I wouldn't be able to go on without the service. I don't know what would happen to me. It's part of me now, part of my wife' (Male participant 4, p6).

Understanding dementia was raised by participants.

'I didn't know what it was (when I was diagnosed), how it was going to affect me.... It upsets me, I speak to God sometimes… you must be doing this for a reason. I won't be any good to anyone. It gets me down a bit' (Male participant 2, p6).

'W gave me all the books, read them for two weeks, started understanding it.... Now that I understand what it is I can accept it' (Male participant 4, p6).

In relation to planning for the future – whether it was future decision-making or planning for future care, only one person with dementia discussed this.

'If things change…natural continuation of my care, more than happy at Morgan Street. I watched them at day care and its brilliant…that's really geed me up knowing that there will be care when I need it. Day care staff make a point of recognising you when you are there. I really want it to be at Morgan Street – the care' (Male participant 4, p7).

In relation to the Talking Points Outcome, this revealed that for the people with dementia using the service, all were able to identify ways in which the service had an impact on their quality of life.

‘In the group there’s different personalities, get close to each other and that’s what keeps us going’ (Male participant 4, p7).

‘It’s all right going to meet folk and going to Craigie Bowling Club’ (Male participant 1 , p7).

‘Keeps me involved and I can’t do that at home’ (Male participant 2, p7).

‘Getting out and about meeting different people and getting transport. If I didn’t have transport I couldn’t go anywhere’ (Male participant 3, p7).

In terms of 'process', people were very keen to praise the support they have had from staff, but this may have been emphasised, as the participants were aware that the researcher was the overall manager:

'Coming into a new situation and finding staff really respect you' (Name not provided, p7).

'Encouraged to be positive. No-one has ever said poor [name]’ (Male participant 4, p7).

'I’m alright the way it is I like the company, if the staff wasn’t good I wouldn’t be long in telling you’ (Male participant 1, p7).

'They look after you really well’ (Male participant 2, p7).

'All the staff are very helpful, I can ask them anything. All the staff in [setting]. In that way it’s really helpful to me’ (Male participant 3, p7).

Considerations: One fundamental flaw in the methodology was that the researcher (practitioner) knew most of the participants through their use of the Resource Centre. The researcher stated that this relationship, as well as an understanding of dementia, helped to ensure that participants could contribute to their full potential. She was mindful of not influencing participant responses, but admitted that this might not have been avoidable. The researcher does not detail how the sample was recruited and there was no evidence that responses and transcripts were checked with another researcher. There is a noticeable lack of detail and depth in participant responses and it is not explicit which aspects of the service individuals are referring to.

Cook G, Brown-Wilson, C, Forte D (2006) The impact of sensory impairment on social interaction between residents in care homes.

Methods: Two small-scale qualitative studies were reported in this paper. The first involved interviews with residents in 4 care homes; the second involved interviews with residents, participant observations and 2 resident focus group interviews.

Data: Thematically coded transcripts from interviews and focus groups with care home residents.

Country: England, UK.

The paper draws on two research studies, receiving an overall medium (+) quality rating. The first study, ‘a hermeneutic inquiry’ examines the meaning ascribed to living in a care home, and the second study, ‘a constructivist study’, explores relationships between residents, families and staff (Authors, page 218). Both studies drew on older people’s narrative accounts to explore their experiences of living in a care home. The aim of this paper was to draw on older people’s narratives to illuminate the experience of living in a care home and the impact that vision and hearing impairments have on the individual’s ability to engage in social interactions with other residents.

Sample size: The first study involved 53 interviews with people aged between 52 and 95 years, who had lived in four different care homes between 1.5 and 6 years. The second study involved 18 residents (aged 70 to 100 years) who lived in one of the care homes within this study. Data in this home was collected through 6 semi-structured interviews with residents, 100 hours of participant observation and 2 resident focus group interviews.

Analysis: Both studies utilised an interpretative framework for the analysis of the participants’ stories of life as a resident. Analysis included examination of cross-cutting themes from both studies.

Findings

The authors suggest that the cross-cutting analysis from both studies highlights the difficulties residents experience in interacting with others, in the home, as a consequence of sight or hearing impairment, and the potential impact this had on feelings of social isolation. They argue this point is illustrated through narratives from two residents, one with sight impairment and the other with hearing loss. They also say that the narratives show the problems these people encountered and how resilient they were in adjusting to their sensory loss and maintaining social interactions.

There are several findings within the main text that relate to how older people discuss their sensory impairments. Below are examples of where explicit reference is made to service use.

Summarising across the accounts, in terms of barriers, the authors comment:

That as staff in care homes are in a position to know people's backgrounds, this helps to facilitate introductions between residents which is positive for building friendships between residents (Authors, p221). The importance of this is exemplified in this account from a resident: 'There are two people I sit near and I can hear to talk with, everyone else is so far away. I would be lost without them. I can talk to [resident 1] because I can hear her. She keeps me up to date, I usually have to ask her what's for dinner. There can be somebody next door to her and I just can't hear them. I should feel lost if there wasn't the three of us. If [resident 1] and [resident 2] weren't here, I would be lost' (Resident, p220).

That residents with marked sensory impairments may be without specific 'label' or diagnosis, making it difficult for staff to acknowledge a resident's problem (Authors, p222).

That key to supporting older people with vision and hearing impairments is "ensuring that equipment is well fitted, positioned correctly and in good working order. However, nurses have been found not to have the awareness, knowledge or skills to achieve this (Authors, p222).

Additionally, residents with sensory impairments spoke about the need for consistency in settings and the environment they were living in: 'I used to go down to the sitting room which is beautifully decorated with lovely armchairs and lovely furnishings and photographs. Really nice you couldn't get it more homely. They keep changing things around which makes things worse for me. Never mind' (Resident, p220–21).

Considerations: Some details are given about how each of the two studies were carried out. However, as the paper reports on two studies, it is not clear what contribution each study made to the findings – they are often merged in the presentation of the results. Additionally, the types of questions asked are not reported and it is not clear how the care homes were selected and sampled or how access to the care homes was obtained. Although the study findings are rich for meeting the study aims, they are thin in terms of providing evidence for barriers to adults using social care. Key analytical themes are explored and reported which are drawn together for the conclusions. However, the conclusions are sparse and the authors could have said more about in what ways practice could be improved. The main conclusion seems to be that more empirical work is required.

Cook G, Thompson J, Reed J (2015) Re-conceptualising the status of residents in a care home: older people wanting to 'live with care'.

Methods: A multiple interview approach, where each resident was interviewed up to eight times over a period of six months, to explore residents' narratives in depth.

Data: Biographical investigation that sought to explore the 'meaning and meaningfulness' that older people attach to their experiences of living in a care home.

Country: UK.

Setting: Diverse types of care home including one 20-bed nursing home, a 40-bed dual registered home, a 78-bed dual-registered home, and a 40-bed nursing/residential and high-dependency elderly care home.

Scoping framework areas: Respect, dignity and control; personalised support; active participation in lived experience of care; care and support for people's needs.

This report presents data from a study rated high (++) quality. This paper examines the complex issues regarding the residential status of care home residents in terms of basic human needs. The aim of the study was to help older people to describe their stories of life within a care home. This was facilitated through the use of a multiple interview approach over a prolonged period. The authors note that not many studies in care homes have such sustained contact with residents to explore their views, and much existing research has focused on the move to a care home, instead of life within a care home. The authors suggest that the emphasis on these factors makes this study unique.

Sample size: Seven women and 1 man resident recruited from diverse types of care home. Aged between 52 and 95 years, residents had lived in these homes for 1.5 to 6 years.

Analysis: Narrative analysis was used to interpret the data. Following each interview, audio recordings were transcribed verbatim, and then coded to get a sense of the stories told and the topics and issues highlighted by the participant. The initial analysis began with researchers getting a sense of the whole data. This was followed by a 'structural analysis' in which the dialogue was examined to illuminate 'what it says' and 'how it was said'. The third stage involved critical in-depth interpretation using the Fundamental Human Needs (FHN) framework in order to analyse narratives in the context of what they said about participants' experiences and desires about the physical, social and self-actualisation needs that 'home' should satisfy. The authors state that this approach provided a broader set of criteria than the Activities of Daily Living (ADL) framework that takes precedence in the care home sector.

Findings

Five themes emerged that collectively establish that residents wanted their residential status to involve 'living with care' rather than 'existing in care'.

The five themes were:

1. 'Caring for oneself/being cared for'

Acute and chronic illness, disability and increased frailty were major reasons that limited participants' ability to carry out one or more self-care or healthcare needs and precipitated a move to a care home. Most participants indicated that being dependent on others in the care home environment was challenging, where staff had little knowledge of their preferences and dislikes. One female resident explained:

'They put things on me and I haven't seen them for months and months. I don't know where they get them from. One day you have a vest on and the next day you haven't. I had no vest on today. She was just going to put my blouse on and I said, "Oh I have to have something on inside my blouse, you can see right through this"' (Resident, p1595).

Participants endeavoured to remain as independent as possible within the care context. A resident said this improved his quality of his life:

'Oh I can control my own life... and that is a big thing. You know I wouldn't like to keep having to ask the staff to take me here or to do this for me or do that. When you can do it yourself it is much better. It makes it, it makes your life more pleasant' (Male resident, p1596).

2. 'Being in control/losing control'

The participants described situations and events where they were able to make decisions and act on them. However, there was also evidence reported that residents did not feel able to have a say about the day-to-day management of the care homes where organisational systems were staff-centred. Another resident reluctantly accepted the dining room seating arrangements:

'I sat at a good table once where they were very nice and friendly. We have single tables now. We used to have a long table where everyone sat down. Now we have tables of four all over and it depends on the table that you sit on …it is not as much fun as before' (Female resident, p1598).

3. 'Relating to others/putting up with others'

Communications with staff were largely classified as 'functional and relational'. Functional interaction, the most widespread, emerged from care practices and was concerned with identifying and dealing with residents' needs. Relational interaction involved sharing personal or topical information that was of mutual interest and opportunities for residents to experience 'companionship and reciprocity within the routine of their daily lives' (Authors, p1600). But this was compromised by high staff turnover and demanding staff workload. For example, one resident described how this had a significant impact on her, making her feel:

'Very upset. You never know who is going to walk through the door when you wake up in the morning and when they bring your breakfast in. You ask their name and you ask that half a dozen times during the day because you have forgotten and the next thing you know they have gone and they don't even say goodbye – they just disappear' (Female resident , p1600).

Participants with limited mobility had little choice regarding contact with other residents and were almost totally reliant on staff to facilitate access to public areas of the home.

4. 'Active choosers and users of space/occupying space'

Separate rooms allowed participants to nurture private lives with family and friends. But small room size restricted their options in terms of furnishings and fittings. Furthermore, some appliances and services were unavailable to residents (for example, private telephone lines and the internet), which meant that some activities could not be kept discreet (for example, telephone conversations using the care home's line). None of the participants had locks on their rooms, and staff often entered residents' rooms without asking; participants, however, felt that this was standard practice and did not complain.

5. 'Engaging in meaningful activity/lacking meaningful activity'

Participants described the 'sameness of it all', as explained below:

'I get up, helped to get ready, have breakfast and then I would be taken to the day lounge. Then lunch, then tea and then back to bed. That is how it is, every day!' (Female resident, p1604).

Most significance was placed on activities that provided a goal or purpose, or created a sense of fulfilment or achievement, for example activities with family and friends. The role of the activities co-ordinator and support of staff were seen as paramount in this respect.

Limited resources affected the range of activities available, for example, transport problems and staffing issues restricted excursions and outings with friends and family.

Considerations: The authors suggest that being reliant on a small sample who lived in four different care home environments where not much was known about the culture and surroundings may mean that generalising from such data is problematic. However, this deficiency has been compensated for by in-depth and sustained contact with interviewees over a long period, which helped to provide new insights into participants' lives, including the challenges. It was only during the later interviews that participants were able to discuss very sensitive issues such as their anticipated death. This was possible as the bond and trust between researcher and participant strengthened, something not attainable in the context of a single interview.

French and Swain (2006). Disabled people's experiences of housing adaptations.

Methods: Qualitative methods using 7 targeted interviews, 4 specifically on housing issues and 3 about the relationship between occupational therapists and service users.

Data: Views of disabled people about housing issues specifically and the relationship between occupational therapists and service users more generally.

Country: UK.

Setting: People's own homes.

Scoping framework areas: Respect, dignity and control; personalised support; care and support for people's needs.

Interview narratives are presented in this chapter which has been scored overall medium (+) quality. The disabled people in the research have had considerable experiences with housing and substantial contact with occupational therapists in the recent past. Four interviews focus specifically on housing issues while 3 others explore the relationship between occupational therapists and clients more generally. The authors aim to gather some ‘real world’ experiences for the purpose of illustrating some of the qualities users value in occupational therapists and some of the problems which may occur in therapy from users’ viewpoints.

Sample size: There is no information on sample size, including age range, types of disability, gender and so on. The researchers state that 7 disabled people were interviewed. The authors state that it was not their intention to provide a representative sample of service users, but to gather some ‘real world’ experiences to illustrate the topic from the view of the user.

Analysis: The authors have not provided any detail on how the data was analysed and therefore a judgement cannot be made on this aspect.

Findings

Barriers: Choice and control

When communication breaks down, or there is a power imbalance, choice and control is challenged. The resistance to the power relationship with the occupational therapists is described in a female participant's experience and words such as ‘battle’:

‘What I did find incredibly difficult to come to terms with was somebody coming into my home and saying, “This needs to be done and this is how it’s going to be done.” I had no say whatsoever to the point where… well one of the things is the front door which is completely flat because I’m in a wheelchair. I could cope with a small rise very easily and I demonstrated that I could manage. What happens now is that whenever you open the door the leaves blow in because it’s so flat. I had quite a long argument, added to which the builder had difficulty finding such a flat front door’ (Participant, p14).

She continues to describe:

‘The only battle that I won, and it was a major argument that held up all the work for about three months, was that they wanted to lower all the work tops in the kitchen to my height and I kept pointing out that there were three other members of the family and I didn’t want to have to do all the work! What we actually did was a carpenter friend of mine put rollout tops under the existing tops so I have something my height and they’ve got something at their height. It was as if I was living on my own and that the property was theirs’ (Participant, p14).

Being listened to

Another participant, describes significant problems in being listened to or believed. For example, she had problems closing the backdoor to her block of flats and the other tenants started to complain that the door was being left open:

‘So I started to get notices pinned on the back door that said, “Please keep this door locked at all times, close the door”. And if I put two wheels over my ramp they would slam the door even if I was going into my garden area and I’ve always had to have keys to get back in. An OT visited me… and I explained that I couldn’t drive the wheelchair and shut the door and she said could they attach a hook thing on to my shoulder that would hook on the door and, if I was able to manoeuvre the chair properly, this hook would grab on to this other thing and the door would shut behind me. And I thought “Well I might get decapitated or something.” I said “I don’t think that’s going to work.” It took many, many months for the OT system to put this right. I had to demonstrate that I couldn’t actually shut the door to three different people…Then they said yes I could have my remote on that door’ (Female participant, p16).

Constrained by the system

A third interviewee felt that occupational therapists are constrained by the system:

‘I think the difficulties have been with the previous OT. She was all too aware of what she was allowed to recommend from a financial point of view and she was very aware of what the process was...But instead of saying… “We aren’t going to get funding for a downstairs toilet until M is eight because that's the way the system works", if she'd said "Yes I really feel that M is entitled to a downstairs toilet, of course he should have a toilet, but I just cannot get it for him," then I could have understood that. But she didn't, she kept saying that until he's eight he doesn't need a toilet downstairs. And she'd turn up with commodes and all sorts of ridiculous equipment' (Female participant, p16).

Power imbalance

The provision of designs and equipment and the type of relationship initiated are elements that are part of the development of a power relationship. For instance, another participant found her occupational therapist distant and rigid and was helped by a friend and her carer when occupational therapy equipment could not be used:

'When I got home the social service OT came and she started as if it was day one with a big assessment when I'd had the whole thing done in hospital. I was ill and in a lot of pain, sick most of the time, couldn't eat, and I couldn't be doing with it. I thought, "Just go away, just go to the hospital and they'll tell you everything you want to know." She was neutral. She was just doing her job with her clipboard. I can't remember her name - she was just a professional. She came back to say that there was a waiting list for this bath thing so I'd have to have bed baths for three months from the carer. Finally this thing arrived, none of us knew it was coming, it came with a man in a van - a lovely, friendly man with this contraption - but it didn't fit. We got to "breaking rule time" then which meant "blow what they said." My friend and my carer got these two boards and they made a slide system to the bath. The OT didn't help one bit. When we told her the contraption wouldn't work she said "Well, that's that then, it will have to be bed baths." She never came again' (Female participant, p17).

Facilitators

Choice, control and partnership

The authors suggest that where user choice and control exists alongside a genuine working partnership with the occupational therapist, creative and satisfactory solutions can be found.

A mother and son's examples portray this where occupational therapists understood and supported their wishes. The motherbelieves that the occupational therapist assigned to her son is constrained by finance, but, despite this, she supports the mother and not the system.

‘She makes recommendations that are clearly based on what she believes to be right and she listens and she’s prepared to alter according to family circumstances. An example of that would be when she originally looked at our old house for rails around the house, she made the recommendation, came back for comments, and took on board what I had to say, and made some alterations. She’s also got off the fence and written to local authorities, complained and pleaded with them to alter curbs, pavements, roads around the house. It is not part of her brief really but she is prepared to do that’ (Mother, p17).

The son describes:

‘When I was being offered accommodation by the local authority and the housing association it was very useful to have the OT there who could say “Well no, that’s not actually suitable for this person.” That I found useful because I felt very pressured to just take somewhere to live whenever I was offered somewhere. I was in crisis and I was thinking “No this isn’t right, this will not work” and I was really worried that I wouldn’t be able to get out…I found that they reassured me and fought my corner, which was to say “Don’t you worry, stop in that short-term accommodation as long as you need to, until it’s right for you, don’t feel pressured to take something that’s 75% of the way towards something you are after if you physically can’t cope with it”…So I think they give you psychological support as well because of their expertise when everyone else was saying, “Well it’s a disabled flat so just get yourself in there”’ (Son, p18).

Considerations: The authors state that they did not intend to provide a representative sample of service users; their aim was to draw on the experiences of a small number of disabled people with considerable experiences with housing issues and contact with occupational therapists. Data collection, methodology and data analysis techniques have not been presented by authors, so it is not possible to draw any conclusions regarding the validity and reliability of the findings. However, these limitations are compensated for by the rich descriptive content of the narratives, with the contexts of the data clearly described and the diversity of perspectives explored.

Institute of Public Care, Oxford Brookes University (2010) Oxfordshire County Council: support to the early intervention and prevention services for older people and vulnerable adults programme: report on study of care pathways.

Methods: Mixed quantitative and qualitative approach.

Data: Secondary analysis of admissions records and interviews with a sample of the care home residents, their informal main carers where available, and care managers.

Country: England, UK.

This aim of this medium (+) quality study was to identify the critical characteristics, circumstances and events that lead to a care home admission in order to provide appropriate services to prevent or delay such an admission. Older people and their carers were asked about circumstances and experiences prior to entering a care home, including: the previous living arrangements of the older person; their health and need for care in the four to five years leading up to admission; the circumstances around the decision to go into care; and whether there were any services or support that they felt could have enabled them to continue living in their own home for longer. The aim of the secondary analysis was to obtain data on a quarter of all admissions across the county over the year prior to the study. The interviews were carried out with 115 older people admitted to a care home in 2008 to 2009, their informal main carers where available, and care managers.

Sample size: A total of 21 interviews, including 7 older people, 8 carers and 8 care managers, were carried out. There were 3 cases where the carers of older people with dementia were interviewed.

Analysis: The completed interviews were transcribed and an analysis of the transcripts carried out using qualitative data analysis software. This was triangulated with the data from the file audit.

Findings

Differences in service delivery by gender:

Page 17, some gender differences are noted in the likelihood of admission to care. For example, it is noted that men were more likely to be admitted to care at an earlier age than women: 54% of men were under 85 years old compared with 36% of women (see Figure 2). While women were a little more likely than men to have been living alone (66% compared to 60%) or with another family member (19% compared to 13%) prior to going into a care; men were more likely than women to have been living with their partner (27% compared with 15%) prior to admission to care. Men were also more likely than women to have been cared for by their partner prior to going into care (17% compared with 10%) but much less likely to have been cared for by a son or daughter (34% compared with 51%).

Page 19: The authors argue that differences between men and women in terms of service use may reflect in part the higher proportion of men who lived with and were cared for by their partner prior to admission.

Page 19: In terms of mobility, men appeared more mobile than women at admission to care: 20% of men were able to walk without difficulty compared with 13% of women, and only 4% were not able to walk at all compared with 17% of women.

Lack of information: A number of carers commented on the lack of information available to them; for example, the availability of accessible respite care and continence pads (Authors, p16).

Problems with take-up: ‘There was a surprisingly limited take-up of intermediate care and telecare recorded in the social care files’ (Authors, p26).

Delays in service: ‘Delays in receiving a service, the shortness of some visits and consistency in who provided care were all negative factors listed by service users’ (Authors, p26).

The authors suggest ‘the conclusions underline the inter-relatedness of health and social care, addressing one without the other is unlikely to lead to successful outcomes’ (Authors, p26).

Considerations: It was unclear how the secondary analysis was carried out and what of the admissions data was analysed. A comment is made on page 1 that ‘It should be noted that the quality of file data depends on the approach of individual staff to recording the data and this obviously creates varying degrees of bias. For example, information prior to admission to a care home may emphasise the severity of an older person's situation in order to ensure that they are considered eligible for admission.' The qualitative part of the study included sections about social services used and support, which is of relevance to this review but other sections (for example, views about primary care) of the research report are not relevant.

Mair M and McLeod B (2008) An evaluation and assessment of deferred payment agreements.

Methods: Small-scale qualitative research study.

Data: One–to-one interviews older people, focus groups with community-based groups of older people, one-to-one interviews with local authority representatives from social work finance, one-to-one interviews with front-line social work staff responsible for advising residents about funding options and arrangements, and one-to-one interviews with other local authority representatives including social work finance and legal service officers.

Country: Scotland, UK.

This aim of this medium (+) quality study was to explore with care home residents and their relatives, their knowledge of, attitudes towards, and experiences of Deferred Payment Agreements (DPAs); to identify barriers and deterrents to applying for DPAs; and to identify potential for increasing uptake of DPAs. As well as specifically asking local authority representatives, care home residents' relatives and the 2 groups of community-based older people about DPAs, interviews and focus groups were also used to seek views on the principle of deferring payments for care home fees. The research was based on 14 local authorities, and used qualitative methods to gather information from residents and their relatives, older people in the community and local authority officials.

Sample size: A sample of 14 local authorities was chosen to participate in the research. Figure 3, page 10 shows 7 'Routinely offer DPAs and have DPAs in place', 3 'Routinely offer DPAs and have no DPAs in place', 2 'Offer DPAs when the resident asks about them', 2 'Never offer DPAs'.

Analysis: Not reported/not clear how this was done.

Findings

The research identified four main barriers to the use of DPAs:

1. Mixed implementation of policy by local authorities: The research has found varying practices across local authorities in terms of offering and promoting DPAs and this is likely to have acted as a barrier to uptake. Further, some local authorities are clearly not offering residents any vehicle by which to defer care home fee payments.

Information and communication: One of the main barriers that exists with respect to individuals applying for a DPA is lack of information being passed by local authorities to residents about the ability to enter into such an arrangement with the local authority in the first place.

Up-front costs associated with DPAs: One of the other main factors deterring care home residents and their families from entering a DPA is the up-front cost associated with setting up a DPA. These include the costs of engaging a solicitor and the cost of arranging a valuation of the property, and may also include any fees charged by the local authority for their legal input in establishing the agreement.

The DPAs process: Relatives who took part in the research who had actually set up a DPA thought that the level of bureaucracy surrounding the DPA process was quite off-putting. The need for care home residents to have capacity to enter into a DPA - or have power of attorney arrangements in place for someone to do this on their behalf – was noted as an issue by local authority staff.

The authors conclude that the need for good quality information and advice to care home residents and their families is paramount, as is good communication from the local authority to the care home resident and their family to supplement this information, to enable care home residents to access the choices available to them.

Considerations: Although some information on sampling is given – in terms of size – it is not clear on what criteria the participants within the local authorities were chosen. The participants seem to have been a mixture of those with and without experience of DPAs. The authors note that while they had hoped to gather the views of stakeholder organisations, neither ‘Help the Aged’ nor ‘Age Concern’ felt that they had sufficient knowledge and experience to contribute to the project. On page 9 it is reported that the original sample was changed but no reflection is made on the effect the sample changes may have had on the results. Overall, the study is relevant and well conducted but the report could have used more quotes (and indication of numbers with same views). Having said that, the perspectives of various stakeholders are clearly represented and each section has a summary bringing together the key points from these perspectives.

Mathie E, Goodman C, Crang C et al. (2012). An uncertain future: the unchanging views of care home residents about living and dying.

Methods: Mixed-methods study.

Data: Views and experiences about the expectations of end-of-life care: Qualitative interviews.

Country: England, UK.

Question area(s): Q2 Barriers to care, Q3 Facilitators to care (and Q1 Views and Experiences).

Setting: Residential care.

Framework areas: Respect, dignity and control; information and communication; active participation in lived experience of care; continuity of care and transitions (including access); care and support for people’s needs.

This study presents analysis of data from an overall medium (+) quality mixed-methods study aiming to explore the range and diversity of views and experiences held by older people about the expectations of end-of-life care, in order to understand if key events or living in a residential environment influenced their views.

Sample size: 63 interviews were carried out with residents from across 6 care homes of various backgrounds where individuals were interviewed up to three times over the year of the study.

Analysis: Data was analysed using the computer package NVIVO to map the data. The analysis involved three stages. First, there was a process of familiarisation and 'decontextualisation' and sorting of data into separate and defined categories that were close to the participants' own categories. Second, comparison was made within and between categories, which enabled the identification of preoccupations, differences and themes. The third stage was the identification of relationships and exploration of tentative hypotheses. Analysis was double checked by searching for conflicting explanations, peer debriefing within the research team, and discussion with the public involvement in research group. This group tested and validated the findings at the end of the study by running three discussion groups with the care home residents (p735).

Findings

Summarising across the narrative accounts, in terms of barriers and facilitators:

Page 737: Living in the past could indicate the person's cognitive state at the time of the interview (theme: Living in the past), when discussing the future could be unsuitable if it was contradicting the person's sense of reality. Therefore, discussions about end-of-life care planning for those residents had to be tailored very differently (Authors).

Page 737: Living in the present. Across the 6 care homes just under half of the residents did not think they could plan for the future (themes: Future is uncertain; Live day to day). For some of this group the future was by definition uncertain, and they were doubtful that future planning would be helpful (theme: Future is uncertain). Questions about the future and planning for end of life in the care home seemed inappropriate to residents who were still unsettled in the care home.

Page 738: In all 6 care homes, a minority of residents were unhappy and depressed about their lives in the care home (theme: There is no future – depressed). For some, loss of purpose and the limited ability to make a contribution were repeated themes in conversations about the future and how meaningless it was, including the fact that care home staff may not have recognised the impact of this. Three older people were clear that they did not wish to be admitted to hospital again after having had negative experiences. It was not obvious as to how, or if, these views had been recorded in the home's care notes (Residents, p739).

Page 739: Most of the residents, when asked if they would like to stay in the care home or go to hospital at the end of their life, said they would choose the former because it was very important to have familiar staff, and they felt the care home environment was a positive one. Despite this, few residents had been asked to sign anything in this respect, and it was not apparent if these wishes were recorded in the care notes. If residents became very ill they might have to be transferred to a nursing home or a hospital, and they felt they had no control or choice over this, with decisions probably being left to a GP. Many residents felt they did not have a choice.

'Yes, I seem to have that [what will be will be] sort of firmly fixed in my mind but I mean I can't do anything so really I just have to cope with whatever crops up, there's no choice is there' (Resident, p740).

Page 740: The choices for end-of-life care are not always clear-cut for people living in a care home, especially where residents are not identified as being, or do not see themselves as being, at the 'end of life'. Many residents were not very worried about or aware of end-of-life care choices. Thirdly, the choices available are far more complex than a simple choice of either/or decisions (Authors).

Page 740: Very few residents said they had had a conversation with the care home staff about end of life, most saying they did not want to, even though some of the care homes were using care home-specific palliative care support tools, including advance care plans. The residents felt that staff might not be that interested, and that family members were the ones to talk to, or that there was nothing to talk about. Residents said that they wanted to have someone to talk to about their past, their life in the care home, or just to be listened to. Despite describing the staff as friendly, they felt they were too busy to engage in the kind of conversation that could lead on to discussion about end of life (Residents).

Page 739: There was one example of where decision-making and the development of a plan were completed with a member of staff. At the first (research) interview the resident in question had been left with some forms to complete; by the second interview she had had a discussion with the manager:

‘If I have a fall and I might be injured I don’t mind going to hospital but I don’t want to be kept in unless I’ve broken something and if they decide I’m dehydrated... rather come back here and be dehydrated, than in hospital. If I die I don’t want to be resuscitated, if you know what I mean’ (2nd interview). By interview three, she had written down her wishes (Female participant).

The research concluded that older people are able to talk about living and dying, over time, but their experience and observation tells them that choice in end-of-life care may be restricted. There was a diversity of views on the amount of engagement with discussion about dying. A degree of acceptance of their situation in the care home seemed to have some bearing on residents’ ability to plan for the future. The findings challenge those that suggest that older people, as they become more unwell, want ‘more’ intervention not less (Winter L and Parker B 2007).

Considerations: The authors state that these findings cannot be easily extrapolated to the wider population. Care staff acted as gatekeepers to residents and the older people involved in the research may have been more eloquent and not in as poor health or cognitively impaired as those who did not take part. (Authors, page 741). Although the care homes spanned a wide range of settings, no distinctions are made between findings from different settings; the findings are just grouped overall into themes. The study assumed that living in a care home, observing other residents dying and experiencing episodes of ill health would, over time, shape how residents talked about their own mortality and their priorities for end-of-life care. The findings contradicted this.

Riazi A, Bradshaw SA, Playford, editors (2012) Quality of life in the care home: a qualitative study of the perspectives of residents with multiple sclerosis.

Methods: Small-scale qualitative study.

Data: Views and experiences of quality of life (QoL) in care homes; interviews.

Country: London, England.

Question area(s): Q3 Facilitators to care (and Q1 Views and Experiences).

Setting: Residential care.

Framework areas: Respect, dignity and control; active participation in lived experience of care; continuity of care and transitions (including access).

This report presents analysis of data from an overall high (++) quality qualitative study aiming to explore how residents with MS perceive their quality of life in the care home, and to develop a conceptual model of quality of life for care home residents with multiple sclerosis.

Sample size: Care homes were selected within a 100-mile radius of London, UK offering nursing care and personal care, with both high and low proportion of multiple sclerosis residents. Participants were recruited through their care home managers. Participants who could not give consent and those who could not follow the interview questions did not take part. Thirty-seven individuals with multiple sclerosis were identified. Twenty-one residents from 10 care homes were interviewed. Recruitment stopped after 21 participants when ‘data saturation was reached’, after which the 21 participants were interviewed. The authors state that this sample size is comparable with other studies using similar methodologies. Five of those who could not complete the interview had speech problems or could not communicate. Eleven could not follow the interview questions (p2097).

Analysis: Participants were interviewed individually in their care homes. Each interview was recorded and verbatim transcribed. The authors alternated between data collection and analysis, which they say allowed them to confirm coding of thematic categories while they were being developed. Two investigators independently coded the transcripts using open coding, by assigning codes to the text based on words or phrases that captured meaning in the data. After coding each transcript, discussions were held between the investigators regarding the emerging categories, as well as the plausibility of the categories against the transcripts, and consensus was reached. This process was repeated for each transcript, and the emerging categories were continually checked for data ‘fit’. The data were analysed using qualitative data analyses software.

Findings

Page 2098: Many participants spoke about the lack of control and choice:

‘The most important thing is for me to go home. This is not a home. In a month, I’ll be in that wheelchair and I’ll be gone’ (Male participant, aged 58).

However, for some they dealt with the lack of choice by accepting it and getting on with things:

‘I don’t enjoy it, I don’t like it, but you have to make the best out of ... the best you can. I mean from my wife’s point of view is, is that I think for her ... it’s not exactly for her it’s, it’s er I can have a quality of life if you like up there in one of those little rooms, listen to the radio or watch the TV, go to bed or whatever’ (Male participant, aged 56).

Others dealt with it by having a strong sense of 'self':

‘I think it’s given me more confidence because one must stick up for oneself, and one could become institutionalised in here’ (Male participant, aged 56).

Some spoke of the benefits of living in a care home in relation to having on tap services:

‘When I was out living with my parents I think I had a physiotherapy treatment, physiotherapy once a fortnight, well what use is that there’s just no use. So I mean here I have it 3 times a week which is fantastic’ (Female participant, aged 45).

Page 2099 covers the theme of care environment and how this affects ‘Engagement in activities’, ‘Privacy’, ‘Feeling safe’ and ‘Personal care’. For example, one person said:

‘I am thinking one huge advantage of this place, as it was purpose built so it’s not, a really old building trying to convert it, but that cannot work every time I’m sure, erm, but having been purpose built so there’s a lot of space erm, the rooms have you seen, the rooms? They’re very good sizes ... Yes the bedroom is excellent and the bathroom’ (Female participant, aged 45).

And some people mentioned improved relationships as a result of being the care home:

‘Well yes, I mean erm I’m glad in hindsight because the last thing I would want to do is er lumber them with me, I’m sure they would’ve erm been happy to look after me, but I don’t think they would like to have to, er tend to me as carers here do, erm I think that’s another aspect that they shouldn’t see their father and in some situations I’d get into’ (Male participant, aged 63).

Page 2100: the authors point to positive attitudes as being key to doing well in care homes:

‘Attitude to residential living is also central to thriving in a care home’ (Authors).

Another key conclusion was the value of support from other residents:

‘Many residents with MS spoke of the importance of social support provided by other residents in the care home to their quality of life , these included other residents with MS but also other residents of the same age and gender’ (Authors).

The authors argue that key to this were the residents being with people of similar characteristics to themselves.

Unlike previous research which showed a negative association between quality of life and moving to a care home, this study found the transition to care home life for multiple sclerosis residents did not necessarily lead to a 'loss of self'.

Considerations: The study is mostly about quality of life but does include some questions about the care home environment, choice and control, which are relevant to this review (see above). Although the care homes spanned a wide range of settings, organisations and Care Quality Commission scores, this is not reflected in the data findings. No distinctions are made between findings from different settings; the findings are grouped overall into themes.

Stevens AK, Raphael H, Green SM (2015) A qualitative study of older people with minimal care needs experiences of their admission to a nursing home with Registered Nurse care.

Methods: Small-scale qualitative study.

Data: Views and experiences of experiences of admission to a nursing home with Registered Nurse (RN) care; interviews.

Country: The study took place in one geographical region in the south of the UK.

Question area(s): Q3 Facilitators to care (and Q1 Views and Experiences).

Setting: Residential care.

Framework areas: Respect, dignity and control; continuity of care and transitions (including access).

This report presents analysis of data from an overall high (++) quality qualitative study aiming to explore the experiences of older people with minimal care needs admission to care homes with registered nurse care in the UK. A key objective was to develop an understanding of why older people with minimal care needs chose to live in care homes with registered nurse care.

Sample size: In total, 12 residents (10 women and 2 men) aged 86 to 99 years participated in the study between August and December 2009. Five were admitted to a care home from hospital and 7 were admitted from their own home.

Analysis: A qualitative inductive methodology using a grounded theory approach was employed in order to gain insight from the participants' perspective. Each interview was recorded and transcribed verbatim into a word-processing file. Non-verbal communication, for example, displays of emotion during the interview, was also recorded in memos and field notes. During the initial coding, the data were broken down, 'fractured' and codes and labels that depicted meaning were assigned to words or phrases. During analysis, the data were constantly compared to other data, allowing the codes to be reviewed and refined. This ensured that the emerging categories and their properties had relevance and 'fit'. Theoretical memos informed category generation and posed questions of the data. Relevant literature informed the emerging categories and is discussed in the results section. As analysis progressed, coding moved towards being 'selective', focusing on those codes that related to emergent main categories in order to identify a core category that linked the data. Only data that held relevance for the emerging theory continued to be incorporated. As the categories became integrated and reduced, only the most relevant remained and were linked to form the core category.

Findings

The paper describes 'turning points' in terms of decision-making to enter residential care. For some the trigger for entering care was being hospitalised or a sudden bout of ill health (p98):

‘The “turning point” for “choosing the path” was described as a result of a health event requiring hospitalisation or a more subtle realisation of the need for alternative arrangements’ (Authors). And one resident said: ‘Because I needed a lot more looking after, than they (family) could give me. Or that the uniformed people (carers) could give me’ (Female participant 1). Others spoke about the need to have people help them make the decision to enter care through information and communication: ‘I wasn’t in a fit state mentally or physically to start making those sort of arrangements even with help. So there just wasn’t any question of it’ (Female participant 2).

The paper goes on to describe how the need for beds in hospitals leads to families and patients being pressured into making quick decisions about what happens on discharge, for example, where they should be discharged to.

Page 99: the authors argue that:

‘Prospective residents and their carers have been shown to benefit from good preparation in advance of the move’ (Authors). And that ‘The way in which the decision to enter residential care and the amount of involvement the participant had in that decision appeared to be important in the “settling in” to residential care. Participants who reported making the decision to enter the care home appeared to have settled more quickly’ (Authors).

One participant stated:

‘I just liked it here. I like the staff here, I think they are wonderful, never find a better place’ (Female participant 3).

The authors go on to argue that those without control and who have no say on the move are the ones who feel less settled.

In the conclusions, the authors say that the transition journey was not the same for everyone and that the circumstances leading to the 'turning point' varied, as did the level of control participants had on the choice of path, which in turn influenced how participants coped with ‘crossing the bridge’ before ‘settling in’ to the care home.

Considerations: Small-scale – only 12 participants included in the study but data is rich in user views. As the study took place in one geographical region in the south of the UK, it may not be representative of other areas of the UK.

Stewart J, McVittie C (2011) Living with falls: House-bound older people’s experiences of health and community care.

Methods: Small-scale qualitative study.

Data: Views and experiences of older people living with falls and using social care services; interviews.

Country: Scotland.

Question area(s): Q3 Facilitators to care (and Q1 Views and Experiences).

Setting: Own home.

Framework areas: Respect, dignity and control, Personalised support.

This report presents analysis of data from an overall medium (+) quality qualitative study aiming to examine the experiences of 8 housebound, community-living older people of post falls.

Sample size: Twenty letters were sent to potential participants, identified by their community physiotherapist, who had been discharged from the service within the previous 6 weeks. Eight people replied, comprising 7 women and 1 man, aged between 67 and 89 years (mean age 84 years).

Analysis: Interview transcripts were analysed manually using interpretative phenomenological analysis, which results in the identification of themes, or patterns of lived experience, that reflect participants' own understandings of the phenomena being studied. An initial reading was undertaken with preliminary observations and any pertinent issues being noted. This process was repeated a number of times. Descriptive labels were used to identify issues, while emerging relationships between issues were noted. The above process was repeated for each transcript. Thereafter connections between similar issues were perceived, resulting in the identification of emerging conceptual themes. Emerging themes were checked against the transcripts. The first author conducted this initial analysis. Thereafter both authors checked the emerging themes and the authors discussed negative cases and agreed how these cases should inform further analysis of the data and further development of the analytic themes. Data analysis stopped at the point at which no new themes could be identified.

Findings

Analysis of the interviews resulted in four major themes: losing independence, losing confidence, losing social identity, and managing a changed self. The below captures quotes related to service use.

Page 274: The authors give examples of participants no longer being able to manage by themselves and growing dependency – typical examples (Participants):

Female participant 1: "For instance my home help does all the shopping, but you dearly want sometime to do your own shopping, things you need yourself" (Female participant 2). : "Now, I'm feeling I'm depending a lot on my daughter and it's a lot on her shoulders because her husband died 2 years ago with cancer, and, and she's had cancer, and I really feel she's had an awful lot on her plate, and now to be landed with me" (Female participant 2).

Page 275: Another female participant, a 75-year-old woman with severe osteoporosis described encounters with home help workers, on whom she was totally reliant for meals and personal care. In describing these encounters, she made clear a lack of attention afforded to her as a person.

"You're just a number—Say for instance, if you were able to make your coffee, you'd maybe have your sandwich and have your coffee later, well everything's put in front of you. It's like being in a home 'There's your meal, take it. Eat it or lump it'" (Female participant 3).

Page 275: While the authors report some respondents (4/8) saying they were ignored or had not received information about their care or were not being listened to by health and social services, they go on to say not all reports were like this:

'Not all interactions were negative, however, with involvement by health and social-care personnel often providing sources of comfort. The following quotations were in response to being asked whether they benefitted from health and social care involvement, and although only two of the participants felt they physically improved, the feeling of being worthwhile and no longer invisible was deemed of greatest benefit' (Authors). For example:

"Interviewer: Has it been useful do you think, the physiotherapy programme? Female participant 4: I would say so. Interviewer: Can you tell me how? Female participant 4: Just the fact that someone was taking an interest in me. Interviewer: What was the best part of having S come out and, you know, having some rehabilitation? Female participant 4: The fact that someone was caring enough to do it." (Participants).

Page 276: The authors state that participants had found ways of coping with loss of identity (for example, through having social services do more for them) by adopting an acceptance of their situation:

'Part of this process of coming to terms involved attributing the possibility of future falls to circumstances beyond their control (Authors). And the authors also said: 'Participants regarded falls almost as risks of life that had to be accepted' and that 'By making sense of their everyday experiences in ways that emphasised the positive aspects of these experiences, the participants were able to maintain personal identity and quality of life' (Authors).

Page 277: An important facilitator highlighted by the authors is care staff enabling individuals to see their own self-worth post falls. For example, they say that:

'Although the rehabilitation programmes in the current study were not able to address the participants' loss of independence and confidence, for the majority of participants the benefit they felt they had received from the multidisciplinary programme was a re-affirmation of their worth, of having someone take an interest in them. This goes someway in overcoming the loss of social identity as a consequence of their dealings with other hospital and social-care staff' (Authors).

Page 278: The authors argue that future fall interventions must not only address physical consequences of a fall but also: 'Be designed so as to ameliorate psychological difficulties, not add to them; delayed and impersonal delivery of even the most carefully designed service is unlikely to be experienced as satisfactory by those on the receiving end' (Authors).

And that the key to this is: 'Promoting [older people's] ability to manage their sense of who they are will thereby allow older people to find continuing meaning in their everyday lives' (Authors).

Considerations: The study is about the views and experiences of a community of older people after they have had a fall, which does not seem to fit the scope for this review. However, the data themes include discussion of how this has affected their use of services and therefore their views of health and social care. The sampling was rather opportunistic because letters were sent to potential participants (who had been identified by their community physiotherapist) discharged from the service within the previous 6 weeks and the authors waited for these people to reply and only those that did reply became part of the study. Apart from the discharge criterion, there is no information about why these people were chosen or recruited – it seems the study took whoever replied to their letters. This could mean that those who replied were individuals who had more to say about using services post fall, which could present a biased picture. Some of the quotes are about service use but as the study was not explicitly about opinions of using services, some of the themes and quotes are not directly relevant to this review. As this is a small sample from one area of the UK, this study cannot say how much this reflects views of other people after falls in other areas of the UK. But the results are presented well for a small-scale in-depth study.

Swinkels A and Mitchell T (2009) Delayed transfer from hospital to community settings: the older person's perspective.

Methods: Small-scale qualitative study.

Data: Perceptions of the effects of delayed transfer into the community, involvement in discharge planning and future community care needs of older people awaiting discharge from hospital. Semi-structured interviews.

Country: South of England.

Question area(s): Q2 Barriers to care (and Q1 Views and Experiences).

Setting: Three hospitals based in two NHS Trusts in the South of England.

Framework areas: Respect, dignity and control; continuity of care and transitions (including access)

This qualitative study of overall medium (+) quality focuses on the perceptions of the effects of delayed transfer into the community, involvement in discharge planning and future community care needs of older people awaiting discharge from hospital.

Sample size: A purposive sampling strategy was used to identify 23 participants, aged 65 years and over, from different categories of delay (for example, waiting for assessment, a care package or a placement in a residential or nursing home) identified in Situation Reports.

Analysis: Data was analysed using the method of phenomenology, which aims to 'preserve the uniqueness of each lived experience of the phenomenon while permitting an understanding of the meaning of the phenomenon itself'' (Banonis 1989, p168). Researchers transcribed their own interviews and annotated these with memos and reflections during this process. Transcripts were imported into NVivo data analysis software. Each researcher first coded their own interviews and then met together to discuss the development of defined data categories, which were comparable across and between researchers and transcripts. Then themes were developed to house the data categories, and these were explored by both researchers to ensure 'compatibility, fit and rigour' (Koch and Harrington 1998).

Findings

Summarising across the narrative accounts, in terms of barriers.

Participants expressed annoyance, frustration, anxiety and low mood at their unfamiliar surroundings, lack of personal privacy, and prolonged loss of autonomy in self-care and usual everyday routines:

‘I didn’t care whether I lived or died ... well, I hoped I died ‘cos there was too much fussing about ... you get up at 6 o’clock in the morning here, and they started turning you about and giving you a wash ... you are mucked about all through the day and not left alone’ (Participant, p48).

Participants placed great importance on being liked by staff and not being perceived as difficult or a nuisance. However, they sometimes expressed frustration and resentment at having to play this role.

‘My daughter comes in and says, “Don’t say a word out of place.” I said, “I don’t”; she said, “I do”, but nobody is going to dictate to me from now on’ (Participant, p48).

Low mood was reflected in a diverse range of emotions (for example, sadness, hopelessness, apathy, grief) and situations; length of hospital stay, reliance on others, loss of personal autonomy, depersonalisation, death of a partner, irreversible change, boredom, routine and loss of productivity (Authors, p48).

Reduction in mobility caused anxiety and frustration, and participants were very aware of the possible harmful effects of lengthy hospitalisation on their health (Authors, p48).

Involvement in planning for community discharge: For those participants waiting to go home, arranging domestic services (for example, help with personal hygiene, washing clothes, shopping), waiting for equipment and lack of general health improvement were generally considered to be the main reasons for delay. Those awaiting a residential care placement talked about waiting for a place that suited the needs of relatives, for example, the placement being convenient for family to visit (Participants, p49). Conversely, social services were perceived by participants to have played a pivotal role in discharge, for example, by providing information or arranging equipment.

Hospital staff: ‘You are going home Monday? Won’t that be great?’ Patient: ‘It will be absolutely wonderful. They delivered a bed and mattress. I couldn’t afford it and they have been wonderful – social services and the OT and physiotherapist’ (p49).

Participants felt that those responsible for their discharge were mainly from outside the hospital. Many felt that nursing staff were too busy or did not have a key role:

‘Nobody tells me (about leaving hospital). I asked them (nurses) but they don’t even know themselves’ (Participant, p49).

There was almost a universal view that individuals could do nothing to influence their discharge from hospital:

‘I am sure they have (taken my views into account), but I have not been in on those meetings or anything. You know it goes to the consultants and the physio, and so and so and so and so. All these people team together to make a decision presumably. I hope I am telling you right’ (Participant, p49).

Transfer to residential or nursing care in particular was seen as a decision made by other people. Social services were seen to be influential and able to control the degree and speed of discharge arrangements. But some participants felt let down and distressed by what they felt were false assurances and delays in organising care and equipment (Participants, p49).

‘They have said they can’t do no more for me. They said you will be going home and next thing they say it is held up by social services. This keeps disappointing me’ (Participant, p50).

Community care needs: Often, when asked about future care needs, participants seemed either to misjudge the nature, amount and frequency of support needed to stay in their own homes or simply wished to carry on as before without any intervention from outside agencies (Participants). Some patients were aware of the complexity of potential future arrangements after having used complex home care packages previously, but felt they had no say or role in the discharge process.

‘They are going to provide me with a person to do my shopping 1 day a week and put the dustbins down, as it is a little way down. Collect my prescriptions. I don’t think there is anything else they have got to do. Oh, I think they did mention washing; they would do washing. They don’t do domestic which they were trying to arrange, but how successfully I don’t know’ (Participant, p50).

Considerations: Only one method of data collection was employed, that is, conversational interviews (Van Manen 1990, Denzin and Lincoln 2003). This lack of triangulation was partly mitigated by other processes built into the research methodology. The analysis of data was undertaken through rigorous processes that had built-in checks between the researchers. Additionally, during the data collection, the researchers continually checked with participants their understanding of the research as well as revisited consent at various points in the research, given that decisional capacity or competence to make decisions could fluctuate at any time.

Wilson C B and Davies S 2009. Developing relationships in long-term care environments: the contribution of staff.

Methods: Small-scale qualitative study.

Data: Views and experiences of how relationships in care homes influence the experience of older people, their families and staff in care homes; interviews.

Country: London, England.

Question area(s): Q3 Facilitators to care (and Q1 Views and Experiences)

Setting: Residential care.

Framework areas: Personalised support; information and communication.

This report presents analysis of data from an overall medium (+) level qualitative study aiming to consider how relationships in care homes influence the experience of older people, their families and staff. The main objective reported in this paper considers how these relationships are developed and the contribution that staff make to this process through the routines of care.

Sample size: Data were collected over two years between 2003 and 2005 from 3 care homes in England reflecting variations in size, location and resident need. Purposive sampling was undertaken within homes to ensure that participants were able to address the research question. Sixteen residents were interviewed.

Analysis: The study used a constructivist design where the different views held by participants were explored and shared to develop a joint construction of how relationships shaped their experiences. As data were collected, transcription and coding were undertaken in parallel within each care home. Units of meaning were arranged into categories for each home. On completion of data collection, the final stage of ‘filling in patterns’ included searching for convergent and divergent opinion, seeking reasons for these discrepancies. This process was documented in a methodological log providing an audit trail to ensure reliability (Lincoln and Guba 1985, p1749).

Findings

Staff adopted three approaches to care delivery and these influenced the type of relationships that were developed between residents, families and staff. The three approaches were described as 'individualised task-centred', 'resident-centred', and 'relationship-centred' (Authors, p1746).

Each of the approaches of care delivery (above) was present across the three homes. But it was the method routinely adopted within each home that seemed to shape the sort of relationships that developed between staff, residents and families. When staff adopted a resident- or relationship-centred approach to care, there was some evidence to suggest that these methods of care delivery reinforced the most positive experiences for residents, their families and staff.

Page 1750: Getting to know the resident through the routines – Staff who developed knowledge about each resident’s personal care routine felt it was a good way of providing good care and anticipating need. However, researcher observations suggested that, for some residents, staff were so task-centred and pressured that attention to personalised care was often lacking. One resident talked about the impact this approach had on her experience of meal times:

'I have dinner more or less on my own…I'm sitting there for ages before my meal and I have no one to speak to. Then when I get it (my meal), the carers are always in a mad rush as though they haven't got time to do it' (Female resident, the Beeches).

Page 1750: Finding out what matters to the resident – Developing an understanding of a resident's life story through, for example, staff using photos to initiate conversations during care routines, helped staff to see the resident as the person they were both in the past and in the present. This helped staff to understand the significance of doing 'the little things' in the residents' care routines and the potential to make a difference to each resident's experience:

'Well a little bit of lipstick, it cheers you up. Oh yes, I've always worn makeup and the girls, they'll sit on the stool and they'll put my cream on my face' (Female resident, Chestnut Lodge, p1750).

Page 1751: Developing shared understandings – This process included planning and organising care routines to take into account the needs of all residents, staff and families. Shared understandings seemed to encourage 'negotiation and compromise', and the development of 'reciprocal relationships'. For example, in one home, if the needs of a resident could not be met as he or she wished, staff were seen to begin a dialogue with the resident which was deeper than just a simple statement such as, 'there are others I have to deal with first' to include an explanation of why the needs could not be met at that time and other choices provided. As the needs of both the residents and staff were identified, this meant that a compromise could be reached and everyone's needs were met within the relationship:

'Just now I asked and they said can you wait until we get G down and I said yes, so they got her down and then they took me. I would hate to think that G was stuck upstairs because I had to go to the toilet' (Female resident, the Beeches).

Considerations: Despite coverage of framework areas which are relevant to this review (see above), for example, personalised support, and active participation in lived experience of care, the main focus of this study is on relationships within the care home context and the impact that this has on experiences, so this study is not directly about the views of service use as such. The care homes in the study encapsulate a diverse range of need in different types of care home settings; however, the findings do not make that explicit, but are simply brought together into general themes.

Evidence statements

The evidence statements were guided using the 6 ‘scoping framework’ (see review background document for GC5) higher order categories:

- Respect, dignity and control
- Personalised support
- Information and communication
- Active participation in lived experience of care
- Continuity of care and transitions (including access to care)
- Care and support for people’s needs.

These themes are represented within the evidence statements that follow. The statements do not speak to individual themes; the statements often reflect several of the themes. Each statement is prefixed with the letters ‘BF’ (which stand for Barriers and Facilitators studies) and a number, which is the statement’s numerical order in the list.

All evidence statements that follow are based on studies that are rich in direct user views.

Evidence statement measures

The evidence statements report two measures: amount and quality. The following conventions were used for amount of evidence:

- 1 to 2 studies - 'small amount'
- 3 to 4 studies - 'some evidence'
- 5 - 'moderate amount'
- 6 and above - 'good amount'.

In terms of quality, if more than 1 paper was used in an evidence statement, an average was taken of the weights assigned for each paper in order to provide an overall measure of quality for the evidence statement. For example, in a statement with 3 papers, if the first were rated medium (+), the second high (++) and the third low (-), the evidence statement would be recorded as ‘medium’ level quality. If 2 papers were scored high (++) and 1 medium (+), the evidence statement would be recorded as ‘high’ level quality. If there were an even number of studies of two quality levels (for example, two high and two medium), the evidence statement would be weighted on the lower side and recorded as ‘medium’ level quality.

Evidence statements from review of literature on views and experiences on barriers and facilitators to good care

BF1	**Transitions between care settings** This evidence statement is based on a moderate amount of overall high-quality evidence. In the first of 5 studies (Mathie et al. 2012 +) explored views of end-of-life (EOL) care and found that very few residential care home residents had control or choice over making care transitions. In the second study (Riazi et al. 2012 ++), which examined quality of life within care homes, a minority of residents described being in a care home as a decision for which they had no choice. The third study (Stevens et al. 2015 ++) of admissions to a nursing home, found that the amount of involvement participants had in decisions to enter care was very important to how well they settled. The fourth study (Beech et al. 2013 ++), which examined care received before, during and after a health crisis, found that many patients and carers were concerned with the quality of acute hospital discharge planning, especially their lack of involvement in this. A fifth study (Swinkels et al. 2009 +) about the effects of delayed transfer into the community, discharge planning and future community care needs of older people awaiting hospital discharge found an ‘almost universal view’ that individuals could do nothing to influence their discharge from hospital. The studies found that lack of control (or perceived lack of control) over decisions made about entering care and/or transitions between care settings can affect how well care users settle into their new environment. Having more control meant that service users were more likely to settle well in ot the new setting.
BF2	**Care home residents on committees** This evidence statement is based on 1 study of medium quality. This study (Abbott et al. 2000 +) explored the views and experiences of adults living in sheltered housing or residential care settings. This study found that information exchange was a problem and not all residents felt they played an active role or were listened to in committees. The study found that perceptions of control and choice can be improved through greater involvement of care home residents in committees, but only if residents play an active role and are adequately informed about them.
BF3	**Services lacking the personal touch** This evidence statement is based on 2 studies, both of medium quality. The first study (Stewart et al. 2011 +) of older people’s experiences of living with falls at home, describes a ‘lack of attention’ in service delivery due to, for example, staff having a lack of time to offer personalised

	care. The second study (Wilson et al. 2009 +), which explored how relationships develop in long-term care environments, found that because staff were so ‘task-centred’, attention to personalised care was often lacking. The studies found that service delivery often lacks the personal touch in different care environments.
BF4	**Engaging care home residents in conversations** This evidence statement is based on some evidence, all of medium level quality. In the first of 4 studies, (Stewart et al. 2011 +) about older people’s experiences of living with falls at home, the authors found that when health and or social care personnel took time to be involved, care home residents felt that they were ‘no longer invisible’ and had a greater sense of ‘self-worth’. Two studies discussed the key role staff could play in facilitating positive experiences of life in care homes through getting to know the residents better; the first was Cook et al. (2006 +) which examined social interactions between residents in care homes and the second was (Wilson et al. 2009 +), which explored how relationships develop in long-term care environments The fourth study (Mathie et al. 2012 +) which explored views of end-of-life (EOL) care, found that very few residents said they had had a conversation with the care home staff about end-of-life, mainly because staff were perceived by residents to be too busy to engage in the kind of conversation that could lead on to discussion about end-of-life. The studies found that engaging care home residents in conversations facilitates good service experience.
BF5	**Community or peer-support** This evidence statement is based on some evidence of overall medium quality. The first of three studies, (Colton 2013 −), which examined experiences of using the early stage support service for adults with dementia, found that peer support and community connections were the key pillars of support in terms of sharing understandings. In the second study (Riazi et al. 2012 ++), which examined quality of life within care homes, found that some people mentioned improved relationships because of being in the care home. The third study (Cook et al. 2006 +), which examined social interactions between residents in care homes, suggests that care home staff have a key role to play in supporting relationships between residents (see BF4). The studies found that community or peer-support can facilitate positive adult wellbeing.
BF6	**Mitigating ‘loss of identity’.** This evidence statement is based on some evidence of medium quality level. In the first of 4 studies, (Abbott et al. 2000 +), explored the views and experiences of adults living in sheltered housing or residential care settings, and found that adults had ‘positive aspirations’ if they were involved in the running of the residence. The second study (Mathie et al. 2012 +), which explored views of end-of-life (EOL) care, found that ‘loss of purpose’ and the ‘limited ability to make a contribution’ were repeated themes in conversations about the future for care home residents. The third study (Swinkels et al. 2009 +), which explored the effects of transfers, discharge planning and future community care needs of older people awaiting discharge from hospital, found that low mood and emotions was associated with reliance on others and loss of personal autonomy. The fourth study (Stewart and McVittie 2011 +) of older people’s experiences of living with falls at home, found that older adults living alone feared a growing dependency and wished they could do more for themselves.

	Additionally, the feeling of having some value and of no longer being invisible was deemed to be of greatest benefit The studies found that giving care home residents a role to play or an activity to be involved in mitigates 'loss of identity'.
BF7	**Knowledge and training** This evidence statement is based on a small amount of evidence of overall medium level quality level. In the first of 2 studies, (Beech et al. 2013 ++), which examined care received before, during and after a health crisis, found that there were notable 'blockages' to connecting social care and primary care services. Patients were discharged home without suitable arrangements for follow-up care and support and there was a lack of knowledge of the existence and function of social services by potential referrers. The second study (Cook et al. 2006 +), which examined social interactions between residents in care homes, suggests that lack of training is a barrier, with nurses being found not to have the awareness, knowledge or skills to ensure equipment is well fitted, positioned correctly and in good working order. The studies found that key professionals lack adequate knowledge and training.

Included studies for these review questions

Abbott S, Fisk M, Forward L (2000) Social and democratic participation in residential settings for older people: realities and aspirations. Ageing and Society, 20: 327–40

Beech R, Henderson C, Ashby S et al. (2013) Does integrated governance lead to integrated patient care? Findings from the innovation forum. Health & Social Care in the Community, 21: 598–605

Blake M, Bowes A, Gill V, Husain F, Mir G (2016) A collaborative exploration of the reasons for lower satisfaction with services among Bangladeshi and Pakistani social care users. Health & Social Care in the Community, Advance online publication. doi: 10.1111/hsc.12411

Colston G (2013) Perspectives on personal outcomes of early stage support for people with dementia and their carers. Edinburgh: Centre for Research on Families and Relationships: 20. Available at: http://www.scie-socialcareonline.org.uk/perspectives-on-personal-outcomes-of-early-stage-support-for-people-with-dementia-and-their-carers/r/a11G0000002W3ZbIAK

Cook G, Brown-Wilson C, Forte D (2006) The impact of sensory impairment on social interaction between residents in care homes. International Journal of Older People Nursing, 1: 216–24

Cook G, Thompson J, Reed J (2015) Re-conceptualising the status of residents in a care home: older people wanting to 'live with care'. Ageing & Society, 35: 1587–1613

French S and Swain J (2006) Disabled people's experiences of housing adaptations. In: Clutton S and Grisbrooke J, editors. An Introduction to Occupational Therapy in Housing. London: Whurr Publishers Ltd

Institute of Public Care. Oxford Brookes University (2010) Oxfordshire County Council: support to the early intervention and prevention services for older people and vulnerable adults programme: report on study of care pathways. Bath: Oxford Brookes University

Mair M and McLeod B (2008) An evaluation and assessment of deferred payment agreements. Edinburgh: Scottish Government Social Research

Mathie E, Goodman C, Crang C et al. (2012) An uncertain future: the unchanging views of care home residents about living and dying. Palliative medicine 26: 734–43

Riazi A, Bradshaw SA, Playford ED (2012) Quality of life in the care home: a qualitative study of the perspectives of residents with multiple sclerosis. Disability and rehabilitation 34: 2095–102

Stevens Alice K, Raphael Helen, Green Sue M (2015) A qualitative study of older people with minimal care needs experiences of their admission to a nursing home with Registered Nurse care. Quality in Ageing & Older Adults 16: 94–105

Stewart J and McVittie C (2011) Living with falls: House-bound older people's experiences of health and community care. European Journal of Ageing 8: 271–9

Swinkels A and Mitchell T (2009) Delayed transfer from hospital to community settings: the older person's perspective. Health & social care in the community 17: 45–53

Wilson CB and Davies S (2009) Developing relationships in long-term care environments: the contribution of staff. Journal of clinical nursing 18: 1746–55

3.3 *Additional analysis: Views and experience of barriers to good care in residential care homes*

Introduction to the review question

This review formed a sub-set of the review work relating to review question 2, with the specific purpose of exploring the barriers related to improving the experience of care for people who live in residential care homes. The question aimed to consider research that systematically collected the views of residents. The Guideline Committee identified that residential care homes were a setting of priority, as people in residential care can be both excluded from research and can also be at particular risk of poor care.

Review question

2. For people who use adult social care services, what are the barriers related to improving their experience of care?

Summary of the review protocol

Barriers to care in residential care settings

See appendix A for full protocols.

Population

Adults aged 18 or over who use social care services.

Intervention

Experience of social care services.

Setting

Residential care settings, including residential care homes, nursing homes, and supported living homes.

Outcomes: Qualitative themes – relevant to review questions 1 to 3

1. Wellbeing and quality of life (related to health, mental health and social wellbeing).
2. Engagement with services and care, including understanding relevant care and management issues where appropriate.
3. Choice and control.

4. Satisfaction of people who use services (including carer, family and advocate perceptions of how satisfied the people who use services are).
5. Perceived and objectively measured independence.
6. Ability to carry out activities of daily living with or without support.
7. Continuity of care.
8. Participation in social and community activities, including training and education, paid and unpaid employment.
9. Resource use.
10. Security and personal safety.

See appendix A for full protocols.

How the literature was searched

The priority group studies relevant to this review question were a sub-set of those already identified as part of review question 2.

How studies were selected

The sub-group of studies for additional analysis were selected from those that were included based on title and abstract and coded as 'residential care'.

Due to the paucity of evidence for this setting, the review team extended the inclusion criteria to include views of people other than people who use services, such as from practitioners that may answer the question on what barriers there may be to good care in residential care settings, 11 studies met the criteria of both answering review question 2 and coded as ‘residential care’ setting.

See appendix B for full critical appraisal and findings tables.

Narrative summary of the evidence

Clark J (2009) Providing intimate continence care for people with learning disabilities.

Methods: Small-scale qualitative study.

Data: Participant observation in residential care homes, staff interviews and analysis of documents (including support guidelines and organisational policies) were used to ascertain the personal care experiences of 6 people with learning disabilities.

Country: England, UK.

This report presents analysis of data from an overall medium (+) quality qualitative study of the provision of intimate continence care for people with learning disabilities. The study aimed to address this broad question: ‘How do adults with severe and profound learning disabilities experience intimate and personal care?’ As the participants were not able to participate directly in the research due to their level of dementia, the data was collected through participant observations of older people in residential care homes. This was supplemented by interviews with staff and analysis of policy guidelines on the provision of intimate care.

Sample size: Data was collected over 10 months, during which time the delivery of intimate and personal care provided to 6 service users by 17 social staff was observed in 2 residential homes.

Analysis: Data was analysed using a combination of approaches from ethnography and grounded theory. This involved searching for themes in the data and grouping them with a coding system. Themes were then grouped into four categories, which formed the basis of an emerging theory. Data collection and analysis were carried out in stages, with each stage giving shape and direction to the next. In this way, the direction of the study can be guided by what is observed. This article presents the themes that relate to dignity in bladder and bowel function care.

Findings

Data findings are presented in themes in which barriers are discussed:

1. Residents being left exposed: Service users were left naked while sitting on the toilet. Authors say this highlights issues of barriers to dignity.

2. Using the toilet as a seat: Not only were service users often left naked on the toilet, but they were also asked to sit on the toilet while other aspects of their care were carried out. Authors question if it is dignified to be shaved or have teeth cleaned while sitting on the toilet. Another key barrier is privacy. The authors argue this practice means it is not possible for residents to use the toilet without being observed by staff.

3. Residents being left waiting a long time for personal care: The study highlights a disjoin between guidelines stating residents are to be asked at regular intervals if they need to use the toilet and what happens in practice, with examples of residents left for long periods without being taken to the toilet.

4. Residents being watched: The policies and procedures in both homes highlighted the need to maintain privacy and dignity during intimate and personal care. However, while doors were always shut while this care was delivered, other staff and service users often entered the room while someone was on the toilet or in the bath. On one occasion, when a man was on the toilet, at least three other people intruded.

5. Lack of discretion: The study highlights evidence of residents being spoken about in terms of their incontinence in public places such as kitchen areas.

The conclusion reached by the authors was that: ‘In order for dignity to be maintained, a service user must be seen as a human being and also that the goal of intimate and personal care must be to give a positive subjective experience, not just to ‘get the job done’.

Considerations: The study is clear in the types of methodology used but not clear how recruitment of residents was made, or how access to the care homes was gained, and there is no discussion of study limitations. Observations were necessary and understandable because the participants could not communicate themselves, but it is unclear how consent was gained and how the observations were carried out. No discussion of how the observations may have affected the participants. Nothing is reported about the context of the residential care home such as size, age and gender profile of the residents. Although the data provide lots of useful narratives reported on barriers and service use that are applicable to this review and the findings link well to the study aims, it is difficult to distinguish which methods elicited which results.

Cooper C, Dow B, Hay S et al. (2013) Care workers' abusive behavior to residents in care homes: a qualitative study of types of abuse, barriers, and facilitators to good care and development of an instrument for reporting of abuse anonymously.

Methods: Small-scale qualitative study.

Data: Qualitative focus groups with 36 care workers from four London care homes, asking about abuse they had witnessed or perpetrated.

Country: England, UK.

This paper reports on a high (++) quality qualitative study examining the types of abuse, barriers, and facilitators to good care. A secondary aim of the study is to test the development of an instrument for reporting of abuse anonymously.

Sample size: Purposive sampling was carried out to include care workers from a range of care settings (private, voluntary, or local authority; nursing or residential; dementia specialist or not) and with different levels of experience. Care home managers from organisations agreed to participate in the research. Care workers employed to give direct (hands-on) care to people with dementia were invited to participate. This included care assistants and nursing staff.

Focus groups were facilitated by 2 to 3 researchers (SH, CC, and DL), lasted 60 to 90 minutes, and had 6 to 13 participants (Table 1: 36 participants in total from 4 focus groups). The four care facilities were as follows: a local authority residential care home for older people with dementia, a charity run residential care home providing personal and dementia care, a private nursing home for people requiring general and dementia nursing, and a private residential care home for older people specialising in dementia care.

Analysis: Data were analysis using a ‘theoretical’ thematic framework approach driven by the researcher’s theoretical or analytic interest in the area. The researchers undertaking the analysis (BD/SH) were from social work and medical psychiatric backgrounds respectively (Braun and Clarke 2006).

Findings

The authors summarise that:

Residents with ‘potentially abusive consequences were a common occurrence, but deliberate abuse was rare’ (Authors, p1).

Residents ‘waited too long for personal care, or were denied care they needed to ensure they had enough to eat, were moved safely, or were not emotionally neglected’. It is also reported that ‘care home staff suggested this was due to insufficient resources’ (Authors, p1).

Abusive practice was reported to be because care workers ‘did not know of a better strategy or understand the resident’s illness’. An example is cited in the paper of a resident at high risk of falls being required to walk as care workers thought otherwise he would forget the skill (Authors, p1).

Care home staff also reported poor institutional practices. An example is cited in the paper of residents not being given enough time to eat meals because of closing times for the kitchen (Authors, p736).

Residents are reported to have waited long lengths of time for personal care, as exemplified by this account: ‘You’re dealing with one person, suddenly there’s something over there ... so one person’s going to get fobbed off ...you can quite easily give the impression that you don’t care ...it’s like a regular thing’ (Focus group with care home staff, p736).

It is also reported that care home staff lacked key information about residents, which led to the delivery of poor care: ‘It’s very complicated to find out what actually residents have got’ (Focus group with care home staff, p737).

The authors comment that staff discussed care workers ‘feeling undervalued, ignored, underpaid, or blamed when things went wrong or not wanting to do the job’ which they felt led to abusive practice: ‘A lot of us are not paid very well. Sometimes I think that a carer would say that this is as far as I go for £6 an hour’ (Focus group with care home staff, p738).

The authors report that ‘most care workers said that they would be willing to report abuse anonymously’. The authors say the tool they developed to enable abuse to be reported anonymously was a success as evidenced by the fact several staff (no number given) in the care homes involved in the study completed it.

Considerations: The study is clear in what is seeks to do but lacks an actual stated aim. It is not clear how responses may have varied by gender or other participant characteristics and the findings have been presented as summarised points. Having said that, the paper provides lots of discussion and examples included about barriers to social care from the viewpoint of carers supported by some good quotes from care home staff (less on residents).

Fleming J, Brayne C and Cambridge City (2008) Inability to Get Up after Falling, Subsequent Time on Floor, and Summoning Help: Prospective Cohort Study in People over 90.

Methods: Mixed-method study of over 75s in their own homes.

Data: 1-year follow-up of participants in a prospective cohort study of ageing, using fall calendars, phone calls, and visits.

Country: England, UK.

The aim of this overall high (++) quality study was to describe the incidence and extent of lying on the floor for a long time after being unable to get up from a fall among people aged over 90. The part of this study relevant to this review is the reported barriers to using call alarm systems in these circumstances (having a fall and having difficulties getting up).

Data were collected on the immediate consequences of falls among participants of a population-based study – the Cambridge City over-75s Cohort (CC75C). The methods have been described in detail elsewhere for the longitudinal cohort (www.cc75c.group.cam.ac.uk). This cohort initially recruited participants through general practices in the 1980s, when they were all aged 75 or over. Repeated surveys since baseline have gathered data on a range of variables including socio-demographic, physical and mental health, function, and detailed cognitive assessment that included the mini-mental state examination. All those who took part in the 2002–2003 survey (90 women and 20 men) were followed up in a prospective study of falls for one year or until death if sooner. Data recorded after each fall included whether the individual who fell had been able to get up without help, how long they were on the floor, any injuries, and whether they called for assistance.

Sample size: 90 women and 20 men aged over 90 (n=110), surviving participants of the Cambridge City over-75s Cohort, a population based sample.

Analysis: Of the fall data, descriptive analysis comparing those who did or did not report falls during follow-up. Differences were examined by age. Associations with not being able to get up unaided after falling and with lying on the floor for over an hour were quantified with logistic regression and with Cox regression for one time-dependent variable. Subjective comments of participants and relatives were coded from verbatim transcripts using framework analysis methods to identify emergent themes concerning the use of call alarms and summoning help.

Findings

Barriers to using alarms arose at several crucial stages:

1. Not seeing any advantage in having such a system, for example: ‘My niece is only next door. I can bang on the wall if I need to call help’ (Participant, p6). Daughter’s comments: ‘She refuses to have a call alarm because she thinks it would keep going off by mistake. She is worried enough about the string pull alarms in each room [sheltered housing scheme] and often won’t turn on the kitchen or bathroom lights in case she pulls the wrong cord by mistake’ (Relative, p6).

2. Not developing the habit of wearing the pendant even if the system was installed. For example, one person said: ‘I have got one but I don’t have to wear it yet, I just hang it on the back of the chair there.’ And another said: ‘I’d already taken it off ready for bed and put it on the bedside tables then I couldn’t reach it.’

3. Not activating the alarm in the event of a fall either as a conscious decision or as a failed attempt. For example, choosing not to use it: ‘I wanted to be able to get up by myself. It took me a long time to get up but I did it in the end. It makes me annoyed if I have to have help’ (Participant, p6). Another person said: ‘I didn’t want to use the call alarm, although I was wearing it, for fear of being taken into hospital’ (Participant, p6).

Considerations: Details of the recruitment and sampling of the longitudinal cohort are reported elsewhere not in this paper – a link is provided. It is reported here as a 'population sample', so it is unclear how far these findings are representative of the population. Response rates for the longitudinal sample are not reported in this paper. Data collection had to rely on recall but authors argue the effect of this was mitigated by the combination of methods – participant and proxy reports by calendar, phone calls, and visiting – and 'achieved remarkably complete data concerning the immediate sequelae of each fall'. Caution must be applied when interpreting the findings related to reported association between risk factors and these consequences of falling because of the small sample size.

Fleming J, Glynn M, Griffin R et al. (2011) Person-centred support: choices for end-of-life care.

Methods: Multi-component qualitative study.

Data: Research methods involved collecting statistics about the number of people who were admitted to hospital and their outcome; a review of existing research on end-of-life care to identify key messages to inform research questions; gathering views on end of life from 8 older people living in independent care homes, 14 relatives and carers and 18 individual practitioners and managers.

Country: England, UK.

This report presents analysis of data from an overall medium (+) level qualitative study, which aimed to collect the views of residents, their carers or relatives of older people living in independent care homes and staff in care homes on the barriers to person-centred support at the end of life and how these barriers might be overcome. This was part of a larger project called 'the Standards We Expect' aimed at guiding the development of systems and processes to support social care service users to determine how their rights and needs are met, through user involvement and negotiation among key stakeholders, and dialogue with a wider network.

Sample size: 33 people and a focus group of a further 7 carers and relatives broken down as follows: 8 service users (6 were female and 2 were male); 14 relatives; 18 individual practitioners and managers. It was conducted over a period of a month in August and September 2007 in five nursing and residential homes.

Analysis: Despite the research being full of rich data, it does not explain how the material was analysed except to say that a report of the findings was published and a seminar held for all stakeholders to review the information.

Findings

Data findings presented in themes in which barriers are discussed:

Residents not wanting to talk about end of life: Many residents said they had not talked about end of life decisions; only some said they had discussed end-of-life care with their relatives or care home staff; none had spoken to their GP. One resident explained:

‘No, I don’t want them to...I have got it on my mind all the time and it doesn’t go away. I don’t like being over-powered with it’ (Resident, p15).

Written documentation: Only one resident had decisions about their end of life in writing. But it was uncertain if these extended beyond the subject of her funeral and will. No one had advanced care directives.

Residents spoke about family deciding what would happen to them when the time came but that in some cases decisions were not written down.

Reluctance of staff to talk with residents about end of life: This was one of the most significant barriers to choice in end-of-life care.

‘It is very difficult when you don’t know them, it is easier when people have been here a little while and you have got to know them a little bit better... if I am doing the general pre-assessment I will probably leave that question until a little bit later on in the assessment...’ (Practitioner, p20).

One resident had planned his end-of-life needs with his son and daughter-in-law and knew that they had been discussed with the care home staff who had ‘not really’ talked these through with him.

Finding the right time to discuss end-of-life wishes: Staff generally felt that end-of-life discussions with residents and relatives were not appropriate when the resident first moves in:

‘We do do the basic care plan within 48 hours of them coming in. But things like end-of-life care we have a specific page in the care plan for death and dying, and so we tend to get to know them a little bit better and speak to the relatives and try to formulate something they are happy with’ (Practitioner, p21).

Concern that relatives were making decisions on behalf of residents: Many relatives were making important end-of-life decisions for their loved one with minimal resident participation, for example in relation to completing paperwork:

‘If they (residents) are capable of signing, if not it would be the next of kin who would be responsible for it’ (Practitioner, p23).

One relative spoke of paperwork about end-of-life decisions being filled in by her family without discussion with the resident, despite nothing to indicate that the older person was incapable:

‘I don’t know whether they (staff) have discussed it with her but we ourselves have signed a form, a ‘no resuscitation.’ … Me and my sisters have spoken about it, we have not discussed it with my father, he is 87, and we decided we didn’t want resuscitation. But I don’t think it has been discussed with her (mother) because I don’t think she would understand. …We haven’t spoken to her because death to my mother is a bit of a no, no, she doesn’t want to know about it’ (Relative, p23).

Staff attitudes. One resident felt that staff attitudes were a barrier to person-centred care at the end of life:

‘Attitude, the attitude of some carers is wrong, they like to boss old people about and say we are in charge, they are not, they are doing a job’ (Resident, p24).

Funding and staffing levels: Some interviewees mentioned a lack of staffing and funding constraints which had a negative effect on good practice in care for people in end-of-life care.

‘We could always do with more resources, we could always do with someone additional to sit with people in the end of life stages, I don’t believe that anyone should be left on their own… that can be a problem’ (Manager, p25).

Agency staff. Support from staff who were acquainted with residents, as the end of their lives neared, seemed to vary between homes.

‘When agency staff are on my mum has sometimes no teeth in, she is a poor eater any way and with no teeth… Since the changeover in January in a short time three hearing aids just disappeared and she is really fretful, she needs her hearing aid and when she hasn’t got it she is really disorientated she is really agitated. So when things happen like that it is really distressing and it happens more when agency staff are on’ (Relative, p27).

People who chose to die at a care home being admitted to hospital. This was a major barrier to choice in end-of-life care. Staff spoke of the need to have the correct end-of-life paperwork signed by all required parties, including GPs to prevent the problem arising where residents were admitted to hospital when they had previously expressed a wish not to be.

Resuscitation: The necessary signed paperwork was not always available for people who had specified a wish not to be resuscitated or for whom resuscitation was not clinically indicated. One traumatic incident occurred where a resident was resuscitated in front of her family, as a DNAR form supplied for an earlier ambulance journey from hospital was no longer valid.

A lack of prior discussion and planning: This could lead to difficult decisions as the end-of-life approaches:

‘...we had an instance that we had a lady who we had to ring 999 for, the lady was nearly 100. And when they all got here ... they were just about to take her off to hospital, and her daughter said ‘No I don’t want her to. Is she going to get better? No, leave her here, I want her to die here where she is loved and cared for’ (Practitioner, p30).

Absence of residents from ethnic minority groups:

‘We haven’t had any experience here… Oh we have, at the time it was a bit of a panic, it was a Jewish gentleman that passed away and we had a bit of a panic trying to find a Rabbi…At the moment if anything happens then we would probably need to refer to the policy book, generally phone round for specific advice or advice from the family hopefully' (Practitioner, p34).

Fear of blame: Several practitioners were worried that if they followed residents' wishes about not being resuscitated or taken to hospital at the end of their lives, this could lead to criticism and blame for neglect for letting an older resident die naturally.

Considerations: The role of the researcher is not clearly described. Description of how data was collected, including interview questions, and topic schedule in focus group, was not detailed. Apart from a mention that a report of the findings was published and a seminar held for all stakeholders to review the information, there is no description of how data was analysed. With the practitioner focus groups, the researchers found it difficult to make contact with managers and from 5 who responded, only 1 manager attended.

Glendinning C, Clarke S, Hare P et al. (2008) Progress and problems in developing outcomes-focused social care services for older people in England.

Methods: Large-scale mixed-methods study.

Data: A postal survey (collected both quantitative and qualitative information) and case studies in six localities, which includes description of the current policy context and discussion of the social care service outcomes desired by older people.

Country: England, UK.

This mixed-methods paper rated high (++) quality reports on a study into the progress of social services departments in England and Wales in delivering outcomes-focused services for older people (Glendinning et al. 2006). The study consisted of a postal survey, which identified over 70 outcomes-focused social care initiatives across England and Wales, and case studies of progress in developing outcomes-focused social care services in six localities. This paper examines some of the practical challenges in the planning, commissioning, and delivery of outcomes-focused social care services and the ways in which they can be addressed.

This paper distinguishes three types of outcomes based on extensive research with older people (Qureshi et al. 1998). Change outcomes, which relate to improvements in physical, mental or emotional functioning; maintenance outcomes, which prevent or delay deterioration in health, wellbeing or quality of life; and process outcomes, which are concerned with the experience of seeking, obtaining and using services.

Sample size: Data was collected between June and December 2005. A postal survey sent to 222 adult social care managers and practitioners in England and Wales known to be interested in developing outcomes-focused services returned 54 responses. Across the six case study sites, 82 staff and 71 service users took part in interviews or discussions.

Analysis: Postal survey data was analysed using into a Microsoft Access database and quantitative data transferred to SPSS for analysis; qualitative data were analysed thematically. For the case study fieldwork 2 researchers compared field notes and gathered accounts for each study site using a common template.

Findings

Service commissioning and change outcomes

All the case study sites had newly established intermediate care and re-ablement services. Staff working in re-ablement and rehabilitation services voiced concerns that, where significant change outcomes had been achieved, these were not always maintained in the provision of longer term support:

'It gets so far, then it’s out of our hands and we can’t follow it through. The end result, we don’t know ...' (Re-ablement service manager, p59).

Service commissioning and maintenance outcomes

Maintenance outcomes are critical in helping older people who need longer term social care support. But significantly the rigid nature of the commissioning and delivery of home care services means that such services are sometimes unable to offer a full range of desired maintenance outcomes (Knapp et al. 2001, Francis and Netten 2002, 2004, Ware et al. 2003). Managers in some sites said that the home care services they commissioned were aimed mainly at physical maintenance rather than wider social or quality of life outcomes. Service users agreed with this and said they would like to get out more but had no one to take them – this was not part of their home care service (p59).

Recently established outcomes-focused provision. Very few examples existed of provision thought by respondents to be outcomes-focused which were older than 3 years. Even in the case study sites, selected because of established outcomes-focused services, users said their spread was sometimes uneven. The outcomes valued by older people appeared most likely to be achieved in services with strong inter professional teams and devolved resources over which staff had extensive control, for example, in re-ablement services, day centres and residential care homes.

Inconsistency between outcomes-focused practice and service user lives

There appeared to be inconsistency between outcomes-focused practice and service users' broader lives. For example, day centres could provide excellent quality services, with strong emphasis on process outcomes for users, but there was a lack of support for users to maintain their own social activities outside the day centre. The researchers pointed to the 'most striking disjunction' between short-term re-ablement services and longer term home care services, where the latter were often seen as rigid and not responsive to users' desired outcomes. In this example, the authors' views concur with that of managers who said that implementing outcomes-focused services required a whole systems vision and strategy (p61).

Interpretation of outcomes

Both the postal survey and case studies showed that 'outcomes' can have different meanings for medical and social care professionals and debates about 'medical' vs. 'social' models had hindered the development of integrated outcomes-focused day services in one site.

Considerations: Good discussion of policy and context on developing outcomes-focused services. Research based on sound knowledge base and previous research (for example, Qureshi et al. 1998) on outcomes-focused services. Robust data collection methods and analysis described in detail. The study was guided by an advisory group of older service users and carers that met three times during the study. However, there were some limitations such as the low response rate (54 from a possible 222 respondents) to the questionnaires, possibly because outcomes-focused initiatives was a relatively new concept – only 10% of the developments had been established for at least 3 years. The low postal survey response rate meant it was not possible to assess the overall extent of such services.

Handley M, Goodman C, Froggatt K et al. (2014) Living and dying: Responsibility for end-of-life care in care homes without on-site nursing provision—A prospective study.

Methods: A mixed-method design of care home residents, care professionals, health professionals, and care home staff.

Data: Interviews with care home staff and health care professionals alongside a review of care home notes for residents.

Country: England, UK.

The aim of this overall medium (+) quality study aimed to describe the expectations and experiences of end-of-life care of older people resident in care homes, and how care home staff and the healthcare practitioners who visited the care home interpreted their role. This is a prospective mixed-method study which tracked older people living in six 6 care homes in the East of England over 1 year. The study ran from January 2008 to September 2010 and data collection in each care home lasted just over 12 months. Residents' care notes and medical records held within the care homes were reviewed at 4 time points over this 12-month period. This paper reports findings from the care notes review and interviews with district nurses, GPs and care home staff. Interviews were semi-structured, digitally recorded and focused on staff experience of providing end-of-life care.

Sample size: A total of 121 residents took part in the study in interviews and by agreeing to the review of their notes from a total population of 257 residents. Ninety residents (74.4%) remained in the study for the full 12 months. Nineteen NHS professionals (3 GPs who were attached to 3 of the 6 care homes, 11 district nurses: including 1 team leader and 1 clinical manager), and 5 palliative care specialist staff working in community homecare teams and hospices linked to the participating care homes, gave consent and were interviewed. In total, 30 care home workers (9 care assistants, 8 senior care workers, 2 activity co-ordinators, 4 deputy managers, 1 assistant manager and 6 care home managers) gave consent and were interviewed.

Analysis: Interviews were transcribed and entered onto Nvivo qualitative data analysis software for organisation prior to analysis. Analysis involved three stages: (i) familiarisation, de-contextualisation and segmenting the data into categories, (ii) comparing categories (both within and between) for common and divergent themes, and (iii) looking at relationships in the themes identified and the practices observed.

Findings

1. The authors report that care home staff were often unclear about which professional should initiate conversations about dying and planning for dying with residents. They report, for example, that, ‘many care home staff hoped that GPs and district nurses would take the lead, at the right moment, even though healthcare professionals were described as only visiting to address specific health events or to undertake interventions, such as wound care’ (Authors, p25).

2. Another barrier to initiating conversations about end-of-life care reported was time. For example, ‘Time restrictions, limited intermittent contact with residents and apparent wellness of residents during initial consultations were all factors that complicated and inhibited discussions on end-of-life care’ (Authors, p26).

3. Page 27 discusses how health care professionals (GPs and district nurses only) get involved at specific times. GPs, for example, visited for medication reviews and changes, while district nurses were more involved in arranging equipment and monitoring. This discussion continues onto page 28 where the authors argue that: ‘The findings presented here indicated that healthcare professionals did value care home staff knowledge, but this did not translate into shared decision-making or where there were concerns about the capacity of the healthcare services to provide ongoing support on how the two groups could work together’ (Authors, p28).

Considerations: This study is limited in studying 6 care homes and associated primary care services in areas that may not be representative. To be able to address such a sensitive topic, our sample of homes was selected from care homes regarded as providing good care with good working relationships with primary healthcare professionals. It did not engage with practice in homes where there were recognised problems with quality of care.

Hart E, Lymbery M, Gladman JR (2005) Away from Home: An Ethnographic Study of a Transitional Rehabiltation Scheme for Older People in the UK.

Methods: An ethnographic study of an intermediate care scheme in 6 residential care homes.

Data: Interviews with older people, service co-ordinator, care home managers, and rehabilitation staff; focus group interview with occupational therapists and community care officers.

Country: England, UK.

The aim of this high (++) quality paper is to explore the perceptions of older people and care home managers about a transitional rehabilitation scheme in Nottinghamshire. The transitional rehabilitation scheme began in 1997. By September 2000 when the evaluation began the project was based in 5 residential care homes for older people, with a sixth unit opened the following year: 4 units had 5 beds, and 2 units had 10 beds. The transitional rehabilitation scheme was located in units that were separate from the ‘normal’ care provided in each residential home. The units were intended to be as much like ‘home’ as possible and were positioned to reduce the possibility of older people on the transitional rehabilitation unit mixing with ordinary residents in the care home. The study was designed to trace the development of the scheme over 2 years, with fieldwork concentrated in two phases, 12 months apart.

Sample size: Altogether 55 people were interviewed, including 17 older people, the service co-ordinator, 7 care home managers and 30 rehabilitation staff (6 occupational therapists, 1 physiotherapist, 6 community care officers, 16 rehabilitation assistants, 1 social worker). In total the authors conducted 58 interviews, including 4 interviews with older people on their return home – one of whom was also interviewed while in transitional rehabilitation – and a group interview with 3 occupational therapists and 4 community care officers. Participants were selected on the basis of their experience and in-depth knowledge of the scheme.

The theoretical purpose behind the sampling strategy was to understand how each of three key groups experienced the scheme – managers, care staff and older people – and explore similarities and differences within and between groups.

Analysis: All taped interviews were transcribed and entered onto NVivo for analysis and thematically coded.

Findings

Key findings: Findings are structured around three emergent themes. The extracts in the paper do not explicitly outline barriers to adult social care. However, the paper does discuss barriers to transitional rehabilitation schemes. The barriers to transitional rehabilitation schemes includes examples from discussions with elderly people or professionals speaking about differences between the transitional rehabilitation service and residential care, which highlights some of the difficulties experienced with adult social care and what was difficult about the experiences of the transitional rehabilitation scheme, as reported by the elderly people.

The authors report that some older people interviewed reported less satisfactory experiences of their time in hospital compared to hospital and care home staff. For example, the transitional rehabilitation was reported 'an unwelcome deprivation of her rights and liberties' (Authors, p1244).

The authors argue that the interviews with professionals 'showed they preferred the work on the TR scheme to their regular work in residential care'. The paper comments that 'rehabilitation required a much more personalised approach, with a particular emphasis on relationship building' (Authors, p1246).

Under the theme titled 'rehabilitation or adaptation?':

a) The authors argue that while occupational therapists assessed people and prepared the individual goal plans, it was usually the rehabilitation assistants who took responsibility for putting the plans into practice and keeping them up to date. Thus, the authors argue, there was potential for the therapeutic goal plans to be translated into something subtly different, 'given that it was put into operation by people who were not professionally trained therapists' (Authors, p1247).

b) The authors argue that the findings suggest that managers and rehabilitation staff perceived the units as being like home but also as training units. For example, ‘rehabilitation assistants used a socially constructed notion of “home” which was abstract and general. By contrast older people used a personally constructed notion of home which was specific and personal to them’ (Authors, p1247).

c) Design of the transitional rehabilitation units was another important factor and barrier to its success, the authors state that: ‘We observed that in two of the units the corridors were very long; during one visit we observed two residents going for a walk around them and getting lost—indeed they passed us three times. In this one purpose built unit the “training kitchen” was so far from the residents’ day-room that it was an effort for them to get there, especially with a frame’ (Authors, p1247).

Conclusions relevant to barriers: The authors conclude that: ‘Policy makers need to be cautious in the development of residential forms of intermediate care, for two linked reasons. First, it should not always be assumed that home is best for all older people. Secondly, it is by no means straightforward to simulate the conditions of home in an institutional environment—especially one that is purpose-built’ (Authors, p1249).

Considerations: The data are rich about the scheme and provide many examples of what older people said about their experiences. Also, while some information and examples are provided about barriers, not all of the paper is about this.

Hearle D, Rees V, Prince J (2012) Balance of occupation in older adults: experiences in a residential care home.

Methods: Single site mixed-methods study using observation, through a process of interval time sampling. Resident views were also collected.

Data: This ethnographic single site case study was set in a privately managed residential care home for the older adults in South Wales. At the time of the study there were 33 residents in the home. All residents spending time in the public spaces in the home were included in the study and observed over a 3-day period.

Country: England, UK.

This report presents data from a low (−) quality level qualitative study which aimed to explore the nature of occupation of care home residents to address the gap in the literature on this topic and to develop a methodology which could be applied to a wider comparative study. This observation was important in understanding the culture of the residential care home (Silverman 2005), which directly affects the quality of life of residents (Hurtley 2007). This single case study design used multiple data collection methods, including systematic observation based on an interval time sampling model (Fulton et al. 2006), which included the types of activities engaged in by residents identified in an initial visit in areas visited by residents; recording of field notes; collecting residents' views. Interval time sampling used both qualitative and quantitative data collection methods.

Sample size: 33 residents in the home, 30 females and 3 males. All residents using the public spaces in the home were included in the study. The manager reported most residents as having mild confusion.

Analysis: The data were analysed using the Statistical Package for the Social Sciences version 12 (Brace et al. 2006). Descriptive statistics were used to analyse the frequencies of activities of the residents and any variation in occupation over the 3 days. The authors used multiple data collection methods with the aim of increasing the reliability of the findings and reduce bias.

Findings

1. Passive atmosphere. The general mood of the public spaces in the home was one of 'passivity'. Televisions were on in both lounges, but few residents seemed to be viewing. One resident commented:

'We leave it on because someone might be interested''. Conversations were occasionally initiated but were brief and the residents always responded actively to care staff who were attending to requests for personal care such as toileting (p128).

2. Total reliance on staff. Residents spoke about how multiple conditions had affected their previously active lives.

‘I used to knit, make all my children’s clothes and loved to go out in the car . . . now I cannot move, I cannot see and my hearing is bad . . . I wait for someone to come and get me from my room’ (Resident, p128).

3. Boredom. Despite positive comments on the care they received, ‘I am well looked after’, residents had little scope to do any activity of interest ‘there is nothing here, I am so bored’ (p128).

4. No interaction. Residents spent a lot of their time sitting quietly or sleeping, with very limited interaction with other residents and negligible if any contact with staff or with visitors. Residents sought help from care staff to get about, such as to use the stair lift to return to their rooms or to go to the dining room. The only activity that was prompted by the care staff was in relation to personal care with an emphasis on toileting (p129).

Considerations: The authors acknowledged the methodological limitations in this study where observation only provided discrete snap shots, albeit over 12 hours, of the activities of residents in 1 care home. The engagement of residents may have been missed in the use of interval time sampling, and comments from residents may represent only the views of an articulate few at the expense of those who were unwilling or unable to participate. As the sample is small and drawn from only one home, the findings cannot be generalised more widely.

Komaromy C, Sidell M, Katz J (2000) The quality of terminal care in residential and nursing homes.

Methods: Small-scale mixed-methods study.

Data: The study ranked as low quality (-) comprised three stages – a postal questionnaire sent to 1000 care homes (Stage 1); interviews with heads of 100 homes (Stage 2); and 12 case studies (Stage 3). Though the authors state that the study is focused on the quantitative data collected from the postal survey, findings from interviews and case studies have also been included.

Country: England, UK.

This research presents data from an overall low (−) quality mixed-methods study which aimed to provide an overview of death and dying in care homes and a detailed analysis of the care available to dying residents, their families and friends. The survey included information on the residents' profile, length of stay, patterns of death, staffing levels and staff qualifications. The data from the interviews included information about resources available for terminal care, reasons for transfer of residents, and knowledge and training in palliative care. The focus of the reporting is on the opinions of staff, mainly heads of homes.

Sample size: Data collected from the postal survey of 1000 homes yielded a response rate of 41% (n=412). Local authority, private and voluntary residential, voluntary nursing (with some NHS beds), and private and voluntary dual-registered homes were included in this study. Interviews were aimed at heads of 100 homes but there is no indication of response rates. There is no information about the samples in the case studies.

Analysis: Apart from the mention of questionnaire data (Stage 1) and interview data (Stage 2) being analysed using the Statistical Package for the Social Sciences (SPSS), there is no actual discussion of the analysis process. However, the diversity of views and content are explored adequately between the different types of care homes.

Findings

Good quality care was influenced by both internal and external factors as follows.

1. Unpredictable nature of care work. Heads of homes noted that the workload varied according to the changing needs of residents, so that a terminally ill resident could place huge demands on staff time. Nursing home residents often had multiple and complex needs associated with extreme old age requiring more care and support.

2. Staff shortage. Increased demands when someone was nearing death included extra nursing care, spending as much time as possible with the resident, and supporting visiting family and friends. Twenty-one per cent of the heads of homes in

private, voluntary, and local authority homes said that poor staffing levels adversely affected the quality of care that staff were able to provide to dying residents (p193).

3. Sharing end-of-life care across staff. Heads of homes expressed that the demands of the work made it desirable for end-of-life care to be shared among several staff members (p194). In particular, the case studies illustrated the challenging nature of end-of-life care at night, where a lot of physical care, such as changing someone who was incontinent and alternating their position to relieve pressure, required more than one member of staff. Attending to residents, especially at night, often meant that residents in other parts of the home were ignored.

4. Lack of knowledge of palliative care. Two-thirds of heads of homes did not understand the principles or practice of palliative care. Of those interviewed who did, they could not see its relevance beyond that of caring for someone with cancer.

5. Dignity. The specific needs of dying residents focused on pain relief, the maintenance of dignity and being attended to, as end of life was imminent. The heads of homes could not easily define dignity, but those who did so most often associated loss of dignity with physical deterioration and decline, which meant that maintaining dignity could be problematic if it is attributed to the ageing process. Many heads of homes assumed that older residents were resigned to death.

6. Home layout and isolation. Many homes were converted from large old family homes and were not always set up to observe residents when they were ill or physically and mentally frail. Homes that were divided into smaller units had created segregated spaces that could increase the isolation of frail and dying residents within the home.

7. Bedrooms. A bedroom’s size, layout and facilities greatly affected the ease with which care was given to someone who was ill.

8. Call alarm. Not all of the residents were able to use the call system, particularly residents who were dying. One resident who was sharing a room with a dying person said that she had to call for help when her room-mate needed it (Resident, p197).

9. Other practitioners. Fifty-two per cent of heads of homes thought that the GP support was mixed. Five homes had 12 practices serving the home residents, and up to 9 GPs from one practice may attend a dying resident. Keeping the same GP practice did not therefore always ensure continuity of care. A minority of the heads of homes thought that the support given by community nurses was limited or that continuity of care was also an issue.

Considerations: The study clearly states in its methodology that its focus is to report on the findings from the postal survey of 1000 homes, but it has included responses from the other stages, that is, interview and case studies. There is no rationale for doing this, and the authors probably did this to embellish the findings from the questionnaires. This makes it sometimes difficult to establish which methods the study findings originate from. Given that the questionnaire findings were the main focus of this study and contained contextual information on the 10,035 residents in terms of residents' profile, length of stay, patterns of death, reasons for transfer of residents as outlined in the methods section, it is surprising that this information has not been reported on. While heads of homes are the focus of the interviews, there seems to be a bias towards reporting from heads of homes in the questionnaires, and the voices of other staff, except one mention of care assistants, appears absent. The process of data collection, including the numbers of researchers and the way they may have influenced findings, are not clearly described.

Popham C and Orrell M (2012) What matters for people with dementia in care homes?

Methods: Small-scale qualitative study.

Data: Interviews and focus groups with care home residents, family carers and care home staff.

Country: England, UK.

This aim of this medium (+) quality study was to determine to what extent the care home environment met the requirements of the residents with dementia, taking into account the views of managers, carers and staff about what they considered important and setting these findings in the context of a standard environmental assessment. Care homes managers were interviewed to seek their views on the most important factors in the environment when caring for people with dementia. Focus groups were carried out in each care home, facilitated by the researcher in order to gather the views of residents with dementia, family carers and staff as to what aspects of the environment they considered most important.

Sample size: Five care homes within Greater London were recruited as a convenience sample through the researcher's networks. Three were nursing homes, of which 2 had specialised dementia beds. One was a residential home with no specialised provision and 1 was a large care home providing residential, nursing and specialised dementia care. Size varied between 35 and 250 beds. All had access to a safe, enclosed garden.

Analysis: Interviews and focus groups were recorded for later transcription and analysis. Each home was evaluated using the SCEAM, an environmental assessment tool covering the physical features of the home, and the practical and social aspects of the homes' functioning. Themes from the interviews and focus groups were identified and compared between groups, and with the environmental assessment scores.

Findings

Key findings: The most common themes identified from the residents and carers groups were the need for activities and outings, staffing levels, and staff training, attitudes and commitment. Managers felt comfort and homeliness were most important features while staff rated health and safety highest. Care homes scored well on the SCEAM for health and safety, and comfort; however, the tool did not cover key aspects such as activities and staff factors.

Themes in relation to barriers:

1. Activity and interaction: The authors comment that: 'Some residents said they were often bored, and family carers also felt residents were under stimulated. Many residents and family carers wanted more social interaction. Carers felt staff did not have time to sit and chat with residents and were often busy with other tasks. Managers recognised this need but felt staff constraints made it hard to find the time. Communication and language difficulties were noted in some homes where residents

and staff might have different native languages and cultures. Staff sometimes expressed frustration that people would not speak English' (Authors, p183).

2. Freedom and safety: 'Many residents felt they would have liked to be able to choose when they wanted to go outside or which room to sit in. In contrast, carers often felt that their relatives were not able to indicate their preferences, particularly as their dementia progressed. Residents expressed frustration at their lack of freedom to do as they wished, and even though all the care homes had safe secure gardens residents were disappointed that they could generally only use them when staff or visitors were able to accompany them' (Authors, p183).

3. Dignity and privacy: 'Managers and staff mentioned the need to ensure privacy for residents while personal care took place but one resident noted "sometimes the carers are rough"' (Authors, p183).

Considerations: Data based on a small sample. Not rich in quotes. Findings from various participants merged into themes. Not clear how sampling was carried out within the homes, that is, how residents, staff or family carers were selected – only the selection of the care homes is described.

Stewart F, Goddard C, Schiff R et al. (2011) Advanced care planning in care homes for older people: a qualitative study of the views of care staff and families.

Methods: Small-scale qualitative study.

Data: Individual semi-structured interviews in older people's care homes of care home staff and the family of residents in care homes exploring views on advanced care planning.

Research Question: Q2: For people who use adult social care services, what are the barriers related to improving their experience of care?

Country: England, UK.

This report presents data from a high (++) quality qualitative study on advance care planning. The aim of the study was to explore the views of care home staff and families regarding advance care planning in homes providing nursing care or personal care only. Thirty-four care homes took part: 16 homes were residential care homes (2 employing nurses), 10 were nursing and 8 were dual-registered. The findings were supported by other research and analysis of policy guidelines on advance care planning.

Sample size: 33 care home managers (1 managed two homes); 29 care assistants; 18 nurses; 15 residents' family and friends were interviewed. In care homes providing personal care only, where nurses were not employed, a community nurse who visited the home was recruited to the study – in all, 10 community nurses were included.

Analysis: Interviews were analysed using the framework analysis approach, which allowed for the exploration of emerging themes while content coding categorical questions and making it possible to compare themes between different groups in the study sample. It comprised five stages: (i) familiarisation; (ii) identifying a thematic framework; (iii) indexing; (iv) charting; and (v) mapping and interpretation. Barriers to advance care planning are themed and compared between different groups in a table.

Findings

1. Dementia. Staff and families identified dementia as a key obstacle to residents taking part in advance care planning discussions.

'Yeah if you ask mum where she'd want to be she'd say with me…she doesn't know she's in a residential home, she thinks…she's in a waiting room from the hospital, waiting to go home…' (Family member of a resident).

Where family, friends and health professionals could potentially make best interest decisions for the resident based on their knowledge of the individual, nurses and managers suggested that families could occasionally overrule residents' wishes where best interest decisions were in conflict with what the resident wanted.

2. Unexpected medical scenarios. Nurses and managers said such situations acted as barriers to meeting certain advance recommendations.

‘Somebody may tell you, “yes I’d be happy to die here”…but if, during an end of life phase they have some terrific bleed…there’s no choice other than sending to hospital…’ (Care manager of a nursing home).

3. Reluctance from residents. Some staff and family felt that residents’ reluctance to discuss advance care planning was probably because of residents’ fear of thinking about death.

‘Some of them, some of them as I say reluctant to respond…I think, maybe they’re afraid…of dying…’ (Nurse in a residential home).

However, family members also thought it was a case of residents not feeling at ease discussing these issues with care home staff.

4. Reluctance from family to engage staff in advance care planning. Some family members thought that care home staff should not be involved in discussions about advance care planning.

‘Don’t’ think that’s the job of the care home staff… “Now you’re in the home we want to know where to send you when you die?” I mean, that would be a very creepy thing to do…’ (Wife of a resident with dementia living in a residential home).

Staff also perceived that at times family members are reluctant to discuss their relatives’ preferences because of a reluctance to accept that their relative was nearing the end of life.

5. Reluctance from staff to discuss advance care planning. Some care assistants expressed hesitation about discussing end-of-life issues with residents, saying that it should be the responsibility of the resident’s family to engage in advance care planning discussions.

6. Managers and nurses thought that some care home staff struggled with advance care planning because of their cultural beliefs.

‘I know there’s other people (staff), some of them they have trouble discussing it…’ (Nurse working in a nursing home).

7. Conflict between family and staff over advance care planning. Care managers and nurses identified this. A common conflict concerned the nurses' and managers' awareness of the resident's wish to die in the care home, but family insisting on a transfer to hospital. Staff felt that families were convinced that their relative would receive better care in hospital. In contrast, staff believed the care home could provide a more comfortable setting for end-of-life care.

'…relatives…they've discussed with you and they've understood what's…the relative [wants]…but at the last minute they've changed their minds, and they think that the hospital will be the best place for their relative…' (Care Manager of nursing home).

Considerations: This was a well-conducted study with clear explanation of research aims, methods, data collection and analysis. Good contextual material explaining the topic and limitations explained. However, the authors acknowledge that a limitation of this research is the absence of residents' views. Fourteen of 41 potential residents were interviewed, but only one resident shared their views about advance care planning during the interview and the other 13 residents did not. Therefore, the authors were not able to include residents' views as part of this study. A couple of reasons put forward was that the questions regarding advance care planning were near the end of a relatively extensive interview schedule, and secondly advance care planning was a topic that was too sensitive for residents.

Evidence statements

The evidence statements were guided using the 6 'scoping framework' (refer to the review background document for GC5) higher order categories:

- Respect, dignity and control
- Personalised support
- Information and communication
- Active participation in lived experience of care
- Continuity of care and transitions (including access to care)
- Care and support for people's needs.

These themes are represented within the evidence statements that follow. The statements do not speak to individual themes; the statements often reflect several of the themes. Each statement is prefixed with the letters ‘RCB’ (which stands for Residential Care and Barriers studies) and a number, which is the statement’s numerical order in the list.

All evidence statements that follow are based on studies that are rich in direct user views.

Evidence statement measures

The evidence statements report two measures: amount and quality. The following conventions were used for amount of evidence:

- 1 to 2 studies - 'small amount'
- 3 to 4 studies - 'some evidence'
- 5 - 'moderate amount'
- 6 and above - 'good amount'.

In terms of quality, if more than 1 paper was used in an evidence statement, an average was taken of the weights assigned for each paper in order to provide an overall measure of quality for the evidence statement. For example, in a statement with 3 papers, if the first were rated medium (+), the second high (++) and the third low (-), the evidence statement would be recorded as ‘medium’ level quality. If 2 papers were scored high (++) and 1 medium (+), the evidence statement would be recorded as ‘high’ level quality. If there were an even number of studies of two quality levels (for example, two high and two medium), the evidence statement would be weighted on the lower side and recorded as ‘medium’ level quality.

Evidence statements from review of literature on views and experience of barriers to good care in residential care homes

RCB1	**Dignity in care homes** This evidence statement is based on 3 studies of medium level quality. The studies found that residents of care homes experience a lack of dignity in care received. In the first of 3 studies, (Komaromy et al. 2000 −) explored death and dying in care homes and care available to dying residents, their families and friends, and found that loss of dignity was reported by heads of homes to be related to the ageing process (for example, deterioration of a person’s condition) and did not consider dignity was related to processes within the homes. Another study (Popham et al. 2012 +), which examined the extent to which the care home environment

	met the requirements of residents with dementia, found that care home staff were sometimes ‘rough’ when delivering personal care to residents. In the third study (Clark 2009 +) of the provision of intimate continence care for people with learning disabilities, residents were left physically exposed when personal care was being delivered, were asked to sit on the toilet while other aspects of their care were carried out, and had their incontinency spoken about openly in public and shared spaces.
RCB2	**Resource constraints in care homes.** This evidence statement is based on a moderate amount of overall medium level quality evidence. In the first of 5 studies, Cooper et al. 2013 (++), asked care workers in 4 focus groups about abuse they had witnessed or perpetrated, and provided examples of how inadequate staffing levels or equipment failure could lead to negative outcomes for residents. The second study (Popham et al. 2012 +), which examined the extent to which the care home environment met the needs of residents with dementia, found that staff had no time to sit and chat with residents. A third study (Handley et al. 2014 ++) describing the expectations and experiences of end-of-life care of older care home residents, and care home staff and visiting healthcare practitioners’ perceptions of their role, found that time restrictions of the latter group was one factor that complicated and inhibited end-of-life discussions. In the fourth study (Komaromy et al. 2000 −) of death and dying in care homes and the care available, heads of homes said that poor staffing levels adversely affected the quality of care provided. In the final study (Fleming et al. 2011 +) about the views of care home residents, their carers or relatives and staff in care homes on the barriers to person-centred support at the end of life, some interviewees mentioned a lack of staffing and funding constraints which had a negative effect on good practice in end-of-life care. The studies found that resource and time constraints affect the quality of care experienced by care home residents.
RCB3	**Abuse in care homes** This evidence statement is based on 1 high quality study by Cooper et al. (2013 ++), which asked care workers about abuse they had witnessed or perpetrated and found that a lack of resources or competing demands led to residents waiting too long for personal care, or being denied care they needed to ensure they were moved safely or were not emotionally neglected. Furthermore, potential abuse existed where staff acted in ways which they judged were better for residents than alternative options, such as coercing residents to accept care, or restraining them as they saw no other way of keeping them clean. . The study found that care home residents can experience abusive practice.
RCB4	**Lead professional in end-of-life care discussions** This evidence statement is based on some evidence of overall high level quality. In the first of 3 studies, (Handley et al. 2014++), which described the expectations and experiences of end-of-life care of older care home residents, reported that despite opportunities to have discussions about end-of-life wishes with residents, care home staff did not think it was possible to say who had lead responsibility to raise the subject. The second study (Fleming et al. 2011 +) about the views of care home residents, their carers or relatives and staff on the barriers to person-centred support at the end of life reported a general reluctance of staff to discuss end-of-life wishes with residents. The third study (Stewart et al. 2011 ++) exploring the views of care home staff and families regarding

	advance care planning in care homes, similarly, noted a reluctance from staff to engage in discussions about end of life wishes with residents. The studies found that there is a lack of clarity over who should be the lead professional in end-of-life care discussions.
RCB5	**Family involvement in end-of-life care decisions** This evidence statement is based on a small amount of evidence of overall medium level quality. In the first of the two studies identified, (Fleming et al. 2011 +) discussed the views of care home residents, their carers or relatives and staff on the barriers to person-centred support at the end of life. Residents generally veered away from discussions about end-of-life care and spoke about family deciding what would happen to them when the time came. In the second study (Stewart et al. 2011 ++) exploring the views of care home staff and families regarding advance care planning in care homes, residents were reluctant to discuss advance care plans and family members were reluctant to involve staff in such discussions. Furthermore, families would occasionally overrule residents' wishes where best interest decisions conflicted with what the resident wanted. The studies found that family members control decisions about end-of-life care, which create barriers to person-centred care.
RCB6	**Delayed personal care in care homes** This evidence statement is based on a small amount of evidence of overall medium level quality. Measured in terms of accounts of service use, the evidence is unanimously negative. In the first of two studies (Clark 2009 +), exploring the provision of intimate continence care for people with learning disabilities, highlighted a difference between what service guidelines recommend and what happened in practice, with examples of residents left for long periods without being taken to the toilet. In the second study (Cooper et al. 2013 ++), examining the types of abuse, barriers, and facilitators to good care, found that residents waited too long for personal care, or were denied care they needed. The studies found that care home residents experience long waiting times for delivery of personal care.
RCB7	**Undervalued care home staff** Measured in terms of accounts of service use, the evidence is unanimously negative. This evidence statement is based on 1 high quality study (Cooper et al. 2013 ++), which examined the types of abuse, barriers, and facilitators to good care. The study reported care home staff feeling undervalued, ignored and underpaid, which they argued impacted on the quality of care being delivered to residents. A culture of blame made staff reluctant to speak out about what may not be working well within residential care home settings. The study found that care home staff feel undervalued which impacts on the quality of care being delivered to residents.
RCB8	**Call alarms** In terms of accounts of service use, the evidence is unanimously negative. This evidence statement is based on evidence from a small amount of overall medium level quality studies. In the first of two studies, (Fleming et al. 2008 ++), describing reported barriers to using call alarm systems in people's own homes after having a fall and having difficulties getting up, found that there was no advantage in having such a system as participants used other methods to ask for help. Call alarms were not effective as participants reported not using or wearing them, and being reluctant to deploy them after a fall. A second study (Komaromy et al. 2000 −) of death and dying in care homes and care available to dying residents, their

	families and friends, found that not all the residents were able to use the call system, particularly residents who were dying, and who relied on others to help. The studies found that call alarms are not always effective or preferred for people who have had a fall at home or for dying care home residents who rely on others for help.
RCB9	**Layout and design of care homes** Measured in terms of accounts of service use, the evidence is unanimously negative. This evidence statement is based on 4 studies of overall mixed quality. The studies found that the layout and design of care homes is a barrier to service use, inhibiting communication and freedom, especially for residents with sensory impairments. In the first of four studies, (Cook et al. 2006 +) drawing on older people's narrative accounts to explore their experiences of living in a care home, found that staff were instrumental in facilitating discussions between residents in care homes, but being effective at doing this was reliant on care home staff having knowledge about residents and taking time to introduce residents to one another and help them maintain those connections). Residents with sensory impairments found it difficult to navigate the care home environment due to the way furniture had been laid out and kept changing. The second study (Popham et al. 2012 +), which examined the extent to which the care home environment met the requirements of residents with dementia, found that residents were restricted in their access and use of the care home, particularly the outside spaces, due to safety fears but that this meant residents felt they had no freedom. The third study (Hearle et al. 2012 −), which explored the nature of occupation of care home residents, found that the general mood of the public spaces in the home was one of 'passivity' and did not foster communication between residents. The fourth study (Komaromy et al. 2000 −) of death and dying in care homes and care available to dying residents, their families and friends, found that care homes that were divided into smaller units created segregated spaces which increased the isolation of frail and dying residents.

Included studies for these review questions

Clark Julie (2009) Providing intimate continence care for people with learning disabilities. Nursing times, 105: 26–8

Cooper C, Dow B, Hay S, Livingston D, Livingston G (2013) Care workers' abusive behavior to residents in care homes: a qualitative study of types of abuse, barriers, and facilitators to good care and development of an instrument for reporting of abuse anonymously. International psychogeriatrics / IPA, 25: 733–41

Fleming J, Brayne C, Cambridge City (2008) Inability to Get Up after Falling, Subsequent Time on Floor, and Summoning Help: Prospective Cohort Study in People over 90. BMJ (British Medical Journal), 337: 1279–1282

Fleming J, Glynn M, Griffin R, Beresford P (2011) Person-centred support: choices for end-of-life care. London: Shaping Our Lives

Glendinning C, Clarke S, Hare P et al. (2008) Progress and problems in developing outcomes-focused social care services for older people in England. Health & Social Care in the Community 16: 54–63

Handley M, Goodman C, Froggatt K et al. (2014) Living and dying: Responsibility for end-of-life care in care homes without on-site nursing provision—A prospective study. Health & Social Care in the Community, 22: 22–9

Hart Elizabeth, Lymbery Mark, and Gladman J R. F. (2005). Away from Home: An Ethnographic Study of a Transitional Rehabiltation Scheme for Older People in the UK. Social Science & Medicine, 60: 1241–50

Hearle D, Rees V, Prince J (2012) Balance of occupation in older adults: experiences in a residential care home. Quality in Ageing & Older Adults, 13: 125–134

Komaromy C, Sidell M, Katz J T (2000) The quality of terminal care in residential and nursing homes. International journal of palliative nursing, 6: 192–200

Popham C and Orrell M (2012) What matters for people with dementia in care homes? Aging & Mental Health, 16: 181–88

Stewart F, Goddard C, Schiff R, Hall S (2011) Advanced care planning in care homes for older people: a qualitative study of the views of care staff and families. Age and Ageing, 40: 330–35

3.4 Additional analysis: Views and experience of people with learning disabilities, including autism

Introduction to the review question

This review formed a sub-set of the review work relating to review questions 1 to 3, with the specific purpose of exploring the views and experiences of people with learning disabilities, including autism. This additional analysis was undertaken because the Guideline Committee identified this group as a group that may be at risk of experiencing poor care.

Review questions

1. Which aspects of the experience of using adult social care services are positive or valued by people who use services?

2. For people with who use adult social care services, what are the barriers related to improving their experience of care? (With specific reference to people with learning disabilities or autism.)

3. For people who use adult social care services, what would help improve their experience of care? (With specific reference to people with learning disabilities or autism.)

Summary of the review protocol

Review questions 1 to 3

See appendix A for full protocols.

Population

Adults with learning disabilities or autism aged 18 or over who use social care services.

Intervention

Experience of social care services.

Setting

All UK settings where care is delivered.

Outcomes: Qualitative themes – relevant to review questions 1 to 3

1. Wellbeing and quality of life (related to health, mental health and social wellbeing).
2. Engagement with services and care, including understanding relevant care and management issues where appropriate.
3. Choice and control.

4. Satisfaction of people who use services (including carer, family and advocate perceptions of how satisfied the people who use services are).
5. Perceived and objectively measured independence.
6. Ability to carry out activities of daily living with or without support.
7. Continuity of care.
8. Participation in social and community activities, including training and education, paid and unpaid employment.
9. Resource use.
10. Security and personal safety.

How the literature was searched

The priority group studies relevant to this review question were a sub-set of those already identified for review questions 1 to 3. The review team identified those studies that included views and experiences of social care expressed by participants with learning disabilities or autism from the mapping of key characteristics of the population groups.

We additionally searched the Social Care Institute for Excellence (SCIE) Social Care TV database, which contained a range of relevant video evidence of people's experiences of social care.

How the studies were selected

In the absence of high-quality research evidence in relation to this population, it was agreed to lower quality study designs for this question. All studies identified for review questions 1 to 3 were therefore re-screened using the lowered quality threshold, aiming to identify papers specific to people with learning disabilities.

Following full text screening there were 10 studies that were specific to people with learning disabilities. These were all qualitative studies, 3 rated as medium quality and 7 rated as poor quality. Narrative summary of the evidence

Narrative summary of the evidence

Gajewska and Richard (2016) Centres for people with intellectual disabilities: Attendees' perceptions of benefit.

Review Question: 1

Methods: Unstructured individual interviews.

Data: Views of people with intellectual disabilities of the benefits of attending day and community learning centres, and whether the stated goals of providing social support, life skills and greater control by attendees over their lives, are being met.

Country: England.

Setting: Day and community learning centres for people with learning disabilities.

Scoping framework areas: Care and support for people’s needs.

Population group: People with learning disabilities.

This report presents analysis of a study rated medium (+) quality. The study aims to explore the perceptions of people with intellectual disabilities of the benefits of attending day and community learning centres, and whether the stated goals of the centre studied by this piece of research, of providing social support, life skills and greater control by attendees over their lives, are being met.

Sample size: Seven people with learning disabilities, 4 male and 3 female described as having 'a mild level of disability’ (Authors, p587). The authors note 'approximate age ranged from 23 to 54 years' (p588). The report stated that people’s true ages were not used in order to protect their anonymity. There is no information about sexual orientation, socioeconomic position or ethnicity.

Analysis: Interviews were transcribed and analysed using procedures common to a Grounded Theory approach (Corbin & Strauss 1990). Open coding was first used to explore emerging themes from the data, followed by selective coding to identify emerging sub-themes of each concept. The relationship between the main themes and sub-themes was noted. Although the process of coding the themes is described, there is no report of the allocation of codes being checked, nor of the neutrality of the researcher being considered as a possible factor in the positive perception of the day centre, which emerges from the study.

Findings

The report provides a list of the themes that it states emerged from the data provided by the interviews, comprising 4 themes (Skills, Social support, Control and Self-image) and 11 sub-themes. However, the report does not supply the findings for all of these headings, and focuses exclusively on themes of 'internal control' and the 3 sub-themes, which come under the theme of 'Self-image'.

The report finds that:

Internal control. Some participants reported having better control over their emotions and behaviours after attending the Centre. This was partially due to greater understanding of others and their perspectives' (p588–9). An example is provided of one participant who became less argumentative and more tolerant of others:

‘People said that, even “J” said I’ve changed. “P” said when I first came here I was abrupt which means quick temper, something to do with temper isn’t it? Yeah, angry. But I calmed down a hell of a lot’ (Participant, p589).

Self-image: confidence. The authors state that 'most participants expressed greater confidence in themselves and their abilities, following the mastery of new skills' and became more confident socially through learning to deal with unfamiliar situations (Authors, p589):

‘[Before attending the centre] I wouldn’t have done the pack bags at Asda and it’s talking to other people because it’s the people who need the bags packing... I wouldn’t have done that couple of years ago but I’d do it now’ (Participant, p589).

Self-image: self-worth. The authors comment that participants spoke about having increasing respect for themselves, which included recovery from maltreatment, and that being praised for their work helped achieve this recovery:

‘Started liking myself... Pff, I never liked myself...Obviously [because of] the way that I’ve been brought up, the way I’ve been treated over the years. That’s all changing and I’m a better person for it. I’m not a bad person’ (Participant, p589).

Self-image: purpose. The authors describe centres providing participants with different opportunities, which gave them a sense of purpose such as enabling them to carry out activities to benefit other people:

‘Yeah it made me more erm happy. I’ve got something to do with my life, like helping other people, raising money for other... erm things to do here and all that so it is–it’s a good thing’ (Participant, p589).

Considerations: The researcher carrying out the interviewees was a volunteer worker at the centre where the research was carried out. Although the researcher states that this allowed the participants to be 'more comfortable and open during the interviews' (p588), the researcher did not deal with other possible impacts of being already known to participants as a volunteer at the centre, for example, they may have been keen to please the researcher by speaking well of the centre, and the participants could have been concerned about possible consequences if they complained about the centre. The study also does not deal with the researcher's own position as a volunteer at the day centre, that is, having a connection with the place, the impact of whose activities is being researched, does not place the researcher in a neutral position. Additionally, although the use of unstructured interviews could allow for full and open exploration of participants' views, details of the actual processes that occurred in the interviews is not provided.

Hebblethwaite A, Hames A, Donkin M et al. (2007) Investigating the experiences of people who have been homeless and are in contact with learning disability services.

Methods: Semi-structured qualitative interviews were conducted with 14 people with learning disabilities who had experienced homelessness.

Data: The aim is to report the experiences of those with learning disabilities that have been homeless, and ascertain their viewpoints of learning disability services in one region, North East of England.

Country: England.

Setting: Community-based services for people with learning disabilities, in this instance temporary accommodation.

Scoping framework areas: Continuity of care and transitions; care and support for people’s needs.

This paper rated low (−) quality is about the experiences of people with learning disabilities who have been homeless, and aims to understand their views of learning disability services in North East of England. The authors' rationale is that 'Although a limited number of reports have indicated that people with learning disabilities or difficulties may be at increased risk of becoming homeless, very little research has been done in the UK with this group of people' (Authors, p26).

Sample size: Fourteen disabled people of whom 12 were male, 2 female. The age group is 21 to 61.

Analysis: Qualitative data from the interviews was analysed using content analysis. Emerging themes from the data were identified through this method and two raters were employed to ensure the reliability of their findings. Authors noted that unique individual experiences were also taken into account in the analysis (Authors, p28). There is no explicit detail about the full analysis.

Findings

Services accessed by disabled interviewees covered the statutory, private and voluntary sector. When the interviews were conducted, 10 of the participants were homeless and 4 had been homeless but were since re-settled. The relevant findings are about outcomes such as: wellbeing and quality of life, engagement with services and care, and support from agencies.

Support within accommodation

Of the 10 participants who were in temporary accommodation, there were mixed experiences of support. General positive experiences were about where staff supported the needs of service users, were contactable and reliable:

'...helped me with a bit of shopping and cooking and that – helped me with money' (Study participant, p30).

Other support mentioned was where staff supported people emotionally, going to appointments, accessing appropriate benefits and organising health needs.

Four of the participants had negative experiences due to staff not being there for them, not listening to their complaints and problems experienced with other residents and feeling misunderstood. Comments to improve services were about having staff to support the individual handle difficult situations within the temporary accommodation, improving the active participation in determining house rules, and having someone to talk to.

Accessing health services

Participants spoke about accessing health services, such as doctor's appointments', hospitals and a community nurse. Five participants spoke about having mental health problems and another 5 having physical conditions. They had been supported through medication and helpful advice. Proximity to medical support was an issue and 1 participant described having difficulty in registering with a doctor's surgery because of being in temporary accommodation.

A recurring theme was the incidence of mental health problems among the study population where people felt anxiety and distress as a result of being in temporary accommodation. The authors suggest that support services and supported accommodation should acknowledge this issue and ensure that interventions for mental health problems are not ignored because of the focus on addressing the learning disability.

Support received from other agencies, family and friends

Significantly, participants spoke of services that they were receiving or from which they previously had support, including social services, community nurse and learning disabilities organisations. Participants expressed satisfaction with social services in helping them find temporary accommodation, access counselling and develop life skills such as budgeting, cooking, shopping and filling in forms. Three participants felt that they needed more support and help with being accommodated through social services.

Considerations: The authors point out that the sample from the 14 interviews is not representative, especially due to the focus of North East of England. This was due partly to difficulties in recruiting interviewees because of the crisis situation of homelessness. The study did not include people from ethnic minorities, while female representation is limited. The absence of information about interviewee characteristics and history makes it difficult to contextualise and thus interpret the data. User views presented do not make explicit which participant is talking. Lastly, there is no detailed description of the study methodology and data analysis.

Hoole L and Morgan S (2011) 'It's only right that we get involved': service-user perspectives on involvement in learning disability services.

Methods: Focus group held with 7 people with learning disabilities recruited from a self-advocacy group and day centre for people with learning disabilities. The focus group was video recorded.

Data: Focus group to explore the lived experiences of people with learning disabilities as users of services.

Country: England.

Setting: Day service and self-advocacy group for people with learning disabilities.

Scoping framework areas: Respect, dignity and control; personalised support; information and communication; active participation in lived experience of care; care and support for people’s needs.

This report presents analysis of a study rated medium (+) quality which draws on data collected for a local audit and has since been published in the British Journal of Learning Disabilities. The aim was to conduct a focus group with service users with learning disabilities in order to ascertain ‘their experiences of services, what was helpful and unhelpful, whether they felt involved and listened to, and suggestions for improving involvement’ (Authors, p6).

Sample size: Seven people with learning disabilities, 4 male and 3 female. ‘Participants had a learning disabilities, could meaningfully participate in group discussions, and had good expressive and receptive communication skills’ (Authors, p6). The authors note there are varied levels of verbal ability and learning disabilities among participants. There is little information about other characteristics such as age, sexual orientation, socioeconomic position or ethnicity.

Analysis: Comprehensive analysis was undertaken where data was recorded, then analysed using thematic analysis (Braun and Clarke 2006). The authors note that non-verbal cues were not analysed, as they were interested only in the narrative. It is significant that analysis was fed back to each participant in an accessible summary of the findings.

Findings

Participants were keen to share their views as widely as possible and gave their consent for these to be shared in this study (Authors, p6).

The insights and experiences of users of services have been grouped according to three key themes: (1) Feelings of unfairness and inequality; (2) Experiences of inclusion and power; and (3) Future visions.

Feelings of unfairness and inequality

Issues expressed were about feeling an imbalance of power where participants had felt that they had been treated unfairly. One participant recalled a previous tenancy he lived in:

‘When you’re trying to talk to staff, I mean this doesn’t happen here but it has happened in the past in the home I did live in, staff completely ignore you and walk away. That is not very nice…’ (Study participant, p7).

Participants reported that they felt reliant on staff to meet their needs but when they did not do this, they felt disappointed:

‘Sometimes I’ve had to wait around that area, it’s like waiting, I wait around for a bus sometimes, sometimes they do come. I just think to myself, “why have I got ready?” It’s just one big slap in the face’ (Study participant, p7).

Some participants spoke about feeling like they were not being treated or ‘afforded the same rights’ as people who do not have a learning disability:

‘When you’ve got two of your friends…and you both want to move and live in a bungalow or out of a care home, I think staff shouldn’t be allowed to say to one of them “no, you can’t do that cos you need a bit more help”. I think it shouldn’t be allowed because whatever help anyone needs, they should be able to get it whether they're in a care home or an ordinary house down this road' (Study participant, p8).

Over half of participants reported feeling that they were not being listened to:

'It's very difficult to get across or to make everybody realise your feelings. Your feelings are not always met at all' (Study participant, p8).

Experiences of inclusion and power

Participants also spoke of positive experiences where they felt empowered by services and professionals, which was generally due to 'accessible information and travel training' (Authors, p8). Explicit provision noted were day services, support workers, occupational therapists, and psychologists:

'The council and OT got all my bungalow set up for me and it didn't cost me any money at all and anybody should have that right' (Study participant, p8).

Participants also referred to their personal and professional network that supported them, which helped them to feel like their voice was being heard and that someone could represent them with making decisions:

'You can talk to your support workers or your friends or family. They will talk to us about any problems like the house, like [names of other residents] – they're always fighting cos they're not get on really well in the house' (Study participant, p8).

In some cases, participants appreciated self-advocacy forums and taking personal ownership over their own power:

'I think that stuff that is easier now though, I think that's partly due again to the parliament and the work we did to get that to happen' (Study participant, p8).

Future visions

Participants explored potentially empowering ways that they could be involved in making decisions:

'Well, I have got my annual review at [name of house], which is the home where I live in [name of town], which I share with three other people. One of them is currently moving out on the 28th of this month and we're having a meeting, my annual review, this Tuesday and I'm going to press that the other two of us in future get involvement in the process when they select the next person to move in. Cos currently that doesn't happen and I feel that it's about time that it did… Certainly in the place that is Supported Living, like we are, it's only right that we get involved rather than get told who we're gonna have' (Study participant, p8).

Additionally, participants wanted to empower others and advocate for service users with different needs:

'My speciality job is – we've all got a Bill of Rights – and mine is for the hard to reach people. I mean people with severe physical and severe challenging needs because they each have the rights of yourselves and in the past they were just put in services or homes or whatever and they didn't get a say in the matter. Well, we're making it – we're making it our business that they get a choice as much as anyone else' (Study participant, p8).

Considerations: The sample is one focus group consisting of 7 participants where there is a brief description of the characteristics of individuals. The user views presented do not distinguish between each study participant, and direct quotes are not contextualised. The discussion highlights the limitations of conducting a focus group where some participants are more domineering. Despite these limitations, the researchers were governed by previous guidance Gates and Waight (2007) and hosted this in a familiar environment to promote participation. The research team noted, 'we found discussion gathered its own momentum and participants had strong views that they wished to share'. The research team was aware of the 'potentially inhibiting effect that the presence of the video-camera could have had' but on the whole felt satisfied that this did not interfere with the group discussions (Authors p7).

Miller E, Cooper S, Cook A et al. (2008) Outcomes important to people with intellectual disabilities.

Methods: Qualitative interviews with service users with intellectual disabilities (and a small proportion of carers supporting the service user) who were accessing various services across five partnerships supporting people with intellectual disabilities.

Services were selected where health and social care staff were working together to deliver an integrated service at the operational level.

Data: Views and experiences of what outcomes service users with intellectual disabilities prioritise.

Country: Scotland and England.

Setting: A range of settings including statutory adult intellectual disabilities teams, day centres, supported living and people's own homes. Service 1: learning disability team, urban north of England; Service 2: Day services, urban south of England; Service 3: L&D team, rural Scotland; Service 4: Day services, rural north of England; and Service 5: Supported living, urban south of England.

Scoping framework areas: Continuity of care and transitions; care and support for people's needs.

This report presents a comprehensive discussion of a study rated medium (+) quality, exploring the outcomes important to people with learning disabilities. This aim of the study was to focus on the views of service users about the outcomes they value and the role of partnerships in delivering these outcomes. The project included service users and a small number of carers from three distinct service user groups: people with learning disabilities, users of services for older people, and users of mental health services. The research summary reported here is focused on people with learning disabilities.

The initial phase of the research project sought to build upon earlier work conducted by the Social Policy Research Unit at York University (SPRU)[14], and to develop and pilot an outcomes-focused interview schedule with service users. The research team involved researchers from the University of Glasgow working with service user researchers and researchers from the learning disabilities advocacy organisation Central England People First (CEPF). The second stage, which is reported here, and using the adapted interview schedule, was to identify whether partnerships were

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[14] Social Policy Research Unit at York University, identified three outcomes: maintenance (support to the quality of life), process (how services are delivered by staff, and change (making things better) (p151). (Nicholas E, Qureshi H, Bamford C (2003). *Outcomes into practice*. York, UK: Social Policy Research Unit, University of York).

delivering outcomes to users. Interviews were conducted across five partnerships supporting people with learning disabilities.

Sample size: Total of 87 people. There is little information about the sample characteristics of the study population. Forty-eight were women and 39 were men service users, and half of them experienced health problems of various kin but no detail was provided.

Analysis: Qualitative data from the interviews was analysed using Nvivo. The analysis and approach appears inductive, applying an initial coding frame with original outcomes to expand and include issues that occurred in interviews. The researchers then recorded reoccurring themes. It is important to note that there was no analysis of data for the interviews conducted by CEPF, so it is unclear how this data is interpreted or incorporated in the findings.

Findings

The research team collected views and experiences from 87 individuals with intellectual disabilities, and in 12 instances both paid and unpaid carers' views were collected as they supported the interviewee. The type of service and number of participants varied between the five study sites. The authors note that the contribution from CEPF focus groups is limited due to the nature of the questions about process outcomes rather than quality of life outcomes, and also because of the possibility that the CEPF is an advocacy organisation:

'...their members were more used to speaking out about experiences' (Authors, p155).

The relevant quality of life outcomes are reported here; these concern employment, social and community activities, safety, where you live, and wellbeing.

Outcomes: Quality of Life

These outcomes most reported were about activity and social contact.

Having things to do

In a large proportion of interviews in each of the five study areas, employment was fundamental and it was reported that some participants would like to have a paid job. Additionally, some participants spoke about their volunteering as their main activity, highlighting the satisfaction in 'having the opportunities to learn life skills with a view to increased independence' (Authors, p153).

Seeing people

In some rural areas, geographical location and transportation were cited as having an impact on social activities which in turn influenced social isolation. Most service users mentioned the importance of regular contact with staff. One service user spoke about having an increased confidence as a result of support from the learning disabilities team in the urban south England setting. One woman living in an urban area in south England commented:

'My key worker will come here and talk, if I want to or the others…if they've got five minutes' (Study participant, p154).

Conversely, two issues were raised which were about the continuity of staff relationships with service users and staff shortages.

Safety

Most participants stated that social contact helped them feel safe, with several interviewees in service 3 commenting that contact with staff improved their feelings. One woman from rural Scotland commented:

'It's helped me to get over my stress… somebody to turn to when I go high. I've got a phone number down if I get any problems' (Study participant, p154).

Where you live/living as you want

Those in supported living reported a positive lifestyle especially having control over their lives. One paid carer (urban south of England) commented on the dramatic communication skill improvements a person had made now that he was in supported accommodation:

‘…he was moved around a few times to different places and it must be so unnerving… he was so unsettled and he was really frightened looking and wouldn’t sleep at nights or anything like that and now he’s been here for a couple of years he’s got used to, he’s more settled. I think it’s the longest time he’s stayed in a place’ (Carer, p155).

Outcomes: How service users were treated in the service (p155)

Valued and treated with respect

Some people with learning disabilities commented on the importance of services treating service users equally, ensuring professionals maintain their confidentiality and convey the right to access services. The authors note that giving people the confidence to believe they have a legitimate right to services is part of the process of showing them that they are respected and valued:

‘I think it’s really good. Because, just because we’ve got learning disabilities doesn’t mean that we should be you know taught differently, like a child or anything like that you know’ (Man, rural north England, Day Services, p155).

Being listened to

Noted by many service users, being listened to is about one-to-one professional support and communication. Findings reported in an urban south of England day service recorded that over half of participants commented that not being listened to can be a problem, which authors suggest is potentially due to resources and staff shortages.

Choice

Choice was a valued outcome. In the focus group conducted by CEPF some participants felt they had ‘little control over their lives in residential care, and therefore placed high value on choice and having a say’ (Focus group, p155). The research team reported that a large proportion of interviewees enjoyed having a variation in activities they can choose, but also the capacity to opt out if they just want to have a day off. Having choice over where they can live was also important.

A man from a day service in the south of England reported that their service had a forum called the ‘Parliament’:

‘The Parliament – you decide what’s good and what’s not good and then you tell the different resource centres and all the places’ (Study participant, p156).

Reliability

Reliability was not spoken about, nor did interviewees have many examples; however, generally positive experiences were noted. Where interviewees had negative experiences, this was due to professionals being late or not turning up, again authors suggest this could be due to resources and staff shortages.

Considerations: This large-scale study (87 interviews) had good, diverse geographical representation, but the characteristics of study participants have not been clearly described. User researchers played a key role in identifying outcomes and designing research tools for this project, but the authors acknowledge that with hindsight, it would have been more useful to have involved them in discussing the approach to the research, especially the nature of their role before the funding application stage.

Norah Fry Research Centre (2010) 'It's all about respect': people with learning difficulties and personal assistants.

Methods: Visits to 6 direct payment schemes to carry out group, individual and pair interviews with: 19 people with learning difficulties; 14 personal assistants or support workers; 9 managers of direct payment support schemes or provider organisations; and 8 parents or carers. Findings from interviews with the 19 people with learning difficulties are provided.

Data: Service users with learning disabilities and their experience of support received through social care.

Country: UK.

Setting: A range of settings in the statutory, voluntary and private sector, including day centres, People First (self-advocacy group) with members who use direct payments, support provider organisation, and a social services department.

Scoping framework areas: Personalised support; active participation in lived experience of care; continuity of care and support for people needs (including access).

Review questions: Paper also addresses review question 3 on facilitators.

This report presents analysis of a study rated low (−) quality from the second stage of a ‘Skills for Support’ project. The aim is to ‘find out more about what makes good support for people with learning disabilities, particularly those who use direct payments or have one-to-one support through organisations or agencies’ (Authors, p1). The research team gathered this data through visiting six direct payment sites, which are referenced in the setting.

The research project was initiated by the Centre for Inclusive Living, an organisation run by disabled people and the research is funded by the Big Lottery. The Norah Fry Research Centre is also a partner of the project. It is important to note that research governance surrounding consent is not considered, nor whether the project sought ethical approval from a relevant research committee.

Sample size: Nineteen interviews were with service users. All participants with a learning disability had some level of support needs and were eligible for social care support. There was a variation of learning difficulty and language ability ranging from differing levels of independence, to one participant with complex needs who was not independent or able to communicate. Most of the interviews were conducted with their personal assistant present.

Analysis: No information was provided.

Findings

Relevant findings are reported under a section dedicated to ascertaining the views of people with learning difficulties. These are reported under three categories:

a) Independence and control; b) Things people did with their personal assistant; c) What people felt about their personal assistant. All participants felt that having a personal assistant present had given them positive opportunities in life.

Independence and control

Questions explored if having 1:1 personal assistant support helped to promote independence. The study found that independence means two different things. The first being about ‘doing things on your own’, which made people feel proud of themselves but it also concerned being able to cope with household tasks unaided, and being ‘left alone’ to get on with things. The following comments illustrate this theme:

‘It’s much better. I can get out a lot more, and do more for myself’ (Study participant, p9).

‘Another thing I do, I do the ironing myself, I do my bedroom, I do my friend’s washing and ironing. Last night I did four hours of ironing’ (Study participant, p9).

‘When I go on holiday every year, and we don’t have to have the staff with us’ (Study participant, p9).

The other aspect of independence was about participants’ relationship with their personal assistant and having a more equal partnership. Participants expressed having choice over day-to-day activities, albeit there was a reported routine for domestic chores and personal care. The author summarises that ‘moving towards greater control and independence has to be done as a joint effort, and we must remember that new skills and attitudes may need to be fostered both in people with learning difficulties and in the staff who support them’ (Authors, p11).

Things people did with their personal assistant

The general support a personal assistant offered participants concerned going out, shopping and money management. When asked what participants want support with, one participant reported that the support received from his personal assistant meant he bought food rather than a vast number of CDs. The authors also highlighted the aspect of emotional support reported by one individual:

‘We chat about how I feel about things, don’t we? I tend to get stressed. I tend to get a little bit stressed – it can’t be helped, can it?’ (Study participant, p12).

Most participants commented that they just ‘go out’ with their personal assistant, providing them with company and structure to their week. In one instance, the personal assistant added a social aspect because they would go to the pub together, meeting up as friends to play pool with the personal assistant’s own friendship circle, adding to the participant reporting feeling included in his community.

Personal assistants were reported to negotiate aspects of their life and advocate on behalf of the participants. Instances where this was necessary were described in the text as being involved with the police: ‘In one case because of mistaken identity; in other cases because of becoming a victim of physical abuse’ (Author, p12).

What people felt about their personal assistant

Notable themes around what qualities participants appreciated were about trust, mutual friendship and equality, and proactivity.

Trust

People with learning disabilities commented on getting to know the person well because of the 1:1 support offered.

Mutual friendship and equality

Participants discussed ‘give and take’, where the relationship was one of mutual friendship and equality. One participant stated he bought his personal assistant a pint in the pub, another commented:

‘It’s about them understanding you, and you understanding them, isn’t it?’ (Study participant, p13).

Proactivity

Participants appreciated having a personal assistant who would ‘sort things out’, but not necessarily make decisions without consulting the person first. The responses varied from people preferring their personal assistant to stay in the background to wanting the personal assistant to:

‘Be quite forward in getting on with things. Not too up front, but just trying to get things sorted for me’ (Study participant, p13).

Considerations: The methodology and analysis is not adequately reported, thus making findings difficult to contextualise and draw conclusions from. The study is small scale.

Social Care Institute for Excellence (2014a) Challenging behaviour and learning disabilities – improving services. SCIE TV Transcript.

The video and transcript are available at: http://www.scie.org.uk/socialcaretv/video-player.asp?guid=b4260f80-1b05-4a9e-9754-aa39efa2e9c8

Methods: This is an illustrative case study and not a primary research study. There is no stated methodology. However, the video does feature scenarios from the life of people with social care needs and those that support them. The video focuses on areas relevant to our review questions on (RQ1) improving experience, and on (RQ2+3) barriers and facilitators.

The overall quality rating is low (−): the video features rich, relevant experience data, but it includes only one case study and no methodological details.

Data: Qualitative data on people’s experiences reported by proxy (support workers and a family member).

Country: England.

Setting: Community support from care workers.

Scoping framework areas: Respect, dignity and control; personalised support; information and communication; active participation in lived experience of care.

Sample size: The video features 4 people with learning disabilities and behaviour that challenges using support services (2 men, 2 women):

- Female participant 1 – profoundly deaf and severely autistic; significant communication needs
- Female participant 2 – learning disability, behaviour that challenges and significant communication needs

- Male participant 1 – Asperger's Syndrome and behaviour that challenges
- Male participant 2 – learning disability

The video also features care workers in residential support services, the mother of a person being supported in a learning disability residential service and: an area manager for residential support services from the National Autistic Society; a service manager for residential support services from the National Autistic Society; and, a professor of learning disability services from the Tizard Centre at the University of Kent.

Analysis: This is an illustrative case study and not a primary research study. No description of analysis is provided.

Findings

Respect, dignity and control

The video describes how challenging behaviour is a result of people having "vulnerabilities which are exacerbated by the way they are supported" (p1).

When people are not able to communicate what they want or need, they can get frustrated and this can lead to challenging behaviour.

The transcript notes that people's experience can be improved when they have choices in all areas of their life:

"...she can show her choice in all aspects of her life, whether it be an activity or whether it is something as small as choosing her breakfast cereal" (Support worker, residential home, p4).

Personalised support

The area manager of one service describes how a personalised approach means "really understand[ing] the history behind the person" which, in turn, enables workers to empathise with them more, and understand what is driving their behaviour.

There are a number of examples of how behaviour that can be seen as challenging – for example, throwing cups, pushing staff, hitting other people – is actually a manifestation of people trying to communicate their needs. The workers describe how they can personalise the way they provide support to respond to people's needs, for example:

- enabling [participant] to use sign language and symbols as a way of telling her support workers what she needs
- monitoring then reviewing incidents of behaviour that challenges, or changes in someone's wellbeing, to identify the triggers and agree a plan of action
- taking [participant] to the day centre in a minibus on her own rather than with the other residents
- making sure that [participant's] day is planned in a structured way, in advance. Giving him a folder with this information in so he knows about what is happening, and about any changes to the plan, so things don't come as a surprise to him
- working with [participant] to improve his motor skills so he can do things for himself, for example, his laundry.

Information and communication

The transcript emphasises the importance of interpreting behaviour that challenges as a manifestation of someone's discomfort, anxiety or other specific need and that good communication can address this.

"If you put the communication in, and make sure that she knows exactly what she is doing at any given time in the day, she is a lot easier, she is a lot calmer...it reduces the anxiety straight away" (Support worker, residential home, p4).

Active participation in lived experience of care

The transcript describes a range of ways in which people are enabled to feed back on their care and support directly. It also highlights the importance of training workers to understand what is a person's own "normal range of behaviours" so that if they notice something that does not fit within that, they know to be concerned and to communicate with the person and those that support them.

"Communication is the key to how you manage consistency" (Manager, Residential Home).

Considerations: The video aims to provide an illustrative example, however, it should be interpreted with caution given the limitations in terms of methodology and sample described above.

Social Care Institute for Excellence (2012) Challenging behaviour and learning disabilities – independent living. SCIE TV Transcript.

The video and transcript are available at: http://www.scie.org.uk/socialcaretv/video-player.asp?guid=6db7a54b-0ba3-468f-95fb-4b823fab9bb6

Methods: This is an illustrative case study and not a primary research study. There is no stated methodology. However, the video does feature scenarios from the life of people with social care needs and those that support them. The video focuses on areas relevant to our review questions on (RQ1) improving experience, and on (RQ2+3) barriers and facilitators.

The overall quality rating is low (−): the video features rich, relevant experience data, but it includes only a small number of participants and settings and no methodological details.

Data: Qualitative self-report data.

Country: England.

Scoping framework areas: Respect, dignity and control; information and communications; active participation in lived experience; continuity of care.

Sample size: Two male service users with learning disabilities and behaviour that challenges:

Male service user 1 – brain damage resulting from traumatic birth; behaviour that challenges

Male service user 2 – profound learning disabilities, autism, behaviour that challenges

The video also features: a member of care team of person with learning disabilities; a social worker supporting someone with learning disabilities; a team manager, and learning disabilities support services. In addition, it features the mother and brother of a person who has had behaviour that challenges, following brain damage at birth, and a professor of learning disability from the Tizard Centre at the University of Kent.

Analysis: This is an illustrative case study and not a primary research study. No description of analysis is provided.

Findings

Respect, dignity and control.

The transcript emphasises the importance of being able to communicate needs, and that behaviour that challenges can result for people with severe learning disabilities when this does not happen.

"...if they can't say to us, back off a minute, give me a break, they might cast around for a way which works, a way that they can use which stops us doing what we are doing, and that way might be hitting us, or screaming at us" (Professor of Learning Disability, p1).

The mother of a person with behaviour that challenges talks about the positive impact made by using direct payments to recruit a specialist team to provide her son, (male service user 1) , with personalised support. The team have a comprehensive plan, "a living document", that describes what he wants and what is important to him in his day-to-day life and experience.

Examples are provided that show the importance and benefit of enabling people to have choice about all aspects of their life.

Information and communications

(Male service user 1's) mother identifies that services could have done more to help earlier in Andrew's life.

Barriers to a positive experience were identified as:

– Lack of training for parents about how to support children with complex needs

– Challenging behaviour leading to exclusion from respite care so "families that have the most difficulty get the least support" (Mother of person with behaviour that challenges, p5).

The academic expert emphasises this, citing positive aspects of support as:

– round-the-clock practical help for families

– access to short breaks

– access to specialist support from skilled, trained workers.

Active participation in lived experience of care

The transcript describes how, with appropriate support in place, (male service user 1) can live in his own home, in the village he grew up in, near his family.

The importance of this is emphasised by the academic expert who notes that, “The best outcome for people whose behaviour presents a challenge is that they are able to live the kind of rich and varied life that we would want for anybody without needing to use their challenging behaviour" (Professor of Learning Disability, p6).

The video also highlights (male service user 2) who, with 24-hour support, is able to live independently. The team supporting him check in on him to make sure he is not socially isolated which could trigger "a very quick sort of spiral to where he was before" (Team Manager, p8).

Continuity of care and transitions

The transcript emphasises how behaviour that challenges can escalate if communication is not addressed, over time and with a lack of consistency.

"Initially, it was just hair pulling and curtain pulling and, as he got older, with the changes in terms of his support, and I guess a lack of consistency in the way he was supported, he started to become destructive and disruptive as well...The new skills he was learning with more difficult behaviours got responses, so it was effective; hair pulling obviously didn't work as well, whereas throwing something had a better impact..." (Mother of person with behaviour that challenges, p2).

Considerations: The video aims to provide an illustrative example, however, it should be interpreted with caution given the limitations in terms of methodology and sample.

ocial Care Institute for Excellence (2009) Personalisation for Someone with a Learning Disability. SCIE TV Transcript.

The video and transcript are available at: http://www.scie.org.uk/socialcaretv/video-player.asp?guid=ed4aa862-69fe-4696-8422-a8a7e7c017be

Methods: This is an illustrative case study and not a primary research study. There is no stated methodology. However, the video does feature scenarios from the life of a woman with learning disabilities and face-to-face qualitative data provided by her family members. The video focuses on areas relevant to our review questions on (RQ1) improving experience, and on (RQ2+3) barriers and facilitators.

The overall quality rating is low (−): the video features rich, relevant experience data, but it includes only one case study and no methodological details.

Data: Qualitative data on a person’s experiences of support, reported by proxy (family members).

Country: England.

Setting: The person’s own home.

Scoping framework areas: Respect, dignity and control; personalised support; active participation in lived experience of care; care and support for people’s needs.

Sample size: one family are included in this video; specifically, a female participant (daughter) who has social care needs and her mother and sister. (Daughter) has Angelman’s syndrome, no speech, partial sight, hyperactivity and epilepsy.

Analysis: This is an illustrative case study and not a primary research study. No description of analysis is provided.

Findings

Respect, dignity and control

(Daughter) has no speech. Her mother describes how important it was to find out from people close to H what she would want from a personal budget.

"We got a written account from everyone, which was quite a moving experience in itself, to get something written by each member of the family and people that were close to (daughter) as to what she would want from this personal budget" (Mother of person with learning disability, p3).

The family describe the significant impact that having a personal budget has had on their ability to enable their daughter to live the life she wants, with her family, at home. They also highlight the benefit this has on other family members.

"We were at the point of (daughter) going into residential care, not because we wanted it to happen but because it was the only way we were going to be able to function as a family. Being able to allow her to develop as a person, go out on her own and have her own life has given me my life back" (Mother of person with learning disability, p4).

Personalised support

The focus of the video is on using a personal budget in a way that best meets the daughter's needs, specifically, this meant:

- being able to pay her sister a wage as a carer to enable (daughter) to be supported by family members rather than external carers (which she didn't like)
- investing in a yurt in the garden so that (daughter) has somewhere to go to socialise with her friends and her sister more independently, but still close to the house
- paying for short breaks so (daughter) can build her independence but her family also get a break.

Active participation in lived experience of care

The mother describes how inconsistency of support was a barrier to a positive experience, specifically, that her daughter did not like it when she was unable to be cared for by her family.

Considerations: The video aims to provide an illustrative example, however, it should be interpreted with caution given the limitations in terms of methodology and sample described above.

Social Care Institute for Excellence (2010) Working With Lesbian, Gay, Bisexual and Transgendered People – People with learning disabilities: A Gay Man's story. SCIE TV Transcript.

The video and transcript are available at: http://www.scie.org.uk/socialcaretv/video-player.asp?guid=c3f92700-3f9a-4b50-ab5e-13a70c952d73

Methods: This is an illustrative case study and not a primary research study. There is no stated methodology. However, the video does feature scenarios from the life of a man with social care needs and face-to-face qualitative data provided by him. The video focuses on areas relevant to our review questions on (RQ1) improving experience, and on (RQ2+3) barriers and facilitators.

The overall quality rating is low (−): the video features rich, relevant experience data, but it includes only one case study and no methodological details.

Data: Qualitative self-report data.

Country: England.

Setting: Community support from care workers.

Scoping framework areas: Respect, dignity and control; personalised support.

Sample size: The video features a man with learning disabilities. The video also features an academic from Bristol University, Norah Fry Research Centre. The video focuses on the needs of lesbian, gay, bisexual and transgendered people.

Analysis: This is an illustrative case study and not a primary research study. No description of analysis is provided.

Findings

Respect, dignity and control

R talks about how needs related to his sexuality were not addressed by care workers.

"...I wanted to talk about having a relationship. And for every single time it was brought up, it always seems to be ‘Well we can talk about that a bit later on’ but we never actually got to the point of talking about it..." (Gay man with learning disabilities, p2).

Personalised support

R talks about taking control of his Person Centred Review by identifying whom he wanted to invite, and being clear about the support he needed in relation to his sexuality.

The academic in the video also described a study in which they found that many lesbian, gay, bisexual or transgendered people with learning disabilities have the same needs and issues as lesbian, gay, bisexual and transgendered people without learning disabilities, and do not get the support they need.

Barriers to getting the right support or living the life you want, were identified as:

- workers and family members not wanting or not being able to talk about these issues with the person (and related to this, homophobia, bullying and discrimination for the person)
- concerns about risk and safety outweighing the focus on what the person wants: "If you say to a support worker, 'I'm going to...hit a couple of gay nightclubs or a couple of gay pubs' the first thing they're going to start thinking of ‘are you safe? What's going to happen?’ ...sometimes they make it scarier, so people don't try things" (Gay man with learning disabilities, p3–4).

Facilitators included:

- clarity in national policy that people need to be given support in respect of sexuality and relationships
- a need to challenge assumptions about who is and who isn't entitled to sex and relationships, and to challenge services to support people in the most personalised way.

Considerations: The video aims to provide an illustrative example, however, it should be interpreted with caution given the limitations in terms of methodology and sample described above.

Williams V and Robinson C (2000) 'Tick this, tick that': The views of people with learning disabilities on their assessments.

Methods: This study, based on interviews with people with learning disabilities, contains three points of data collection; however, the findings are hard to interpret because the authors seem to be reporting the findings from several interrelated studies.

Data: Views of people with learning disabilities of community care assessments and service reviews otherwise known as Individual Programme Plans (IPPs).

Country: UK.

Setting: Five local authority areas, no detail specified.

Scoping framework areas: Respect, dignity and control; continuity of care and transitions.

Review questions: Paper also addresses review questions 2 and 3 on barriers and facilitators.

The data reported in this qualitative low (−) quality study are from a research study called ‘In Their Own Right’, carried out from 1998 to 1999. The study aimed to ascertain the impact of the Carers (Recognition and Services) Act (1995) on families that include someone with a learning disability and sought the views of 51 carers and the people they cared for. This paper focuses on the views of the people with learning disabilities and compares them with the overall findings from the interviews with carers. A final phase of the study included revisiting 45 of the 51 families to establish the outcomes of their assessments after one year, and do follow-up interviews with all the people with learning disabilities who had experienced significant changes, such as a move from the family home since the researchers' first visit (n=6).

Interviews were carried out soon after the carer had received a carer’s needs assessment. The authors state that it is possible that the Carers Act has also affected the rights and interests of people with learning disabilities who live in the family home. This is why the fuller study examined the assessment process from the point of view of both the carer and of the person they cared for reported in Williams (1999) and Williams and Robinson (2000).

Sample size: 46 people with learning disabilities, 25 of these individuals were also interviewed following a service review or Individual Programme Plan (IPP). The age range of individuals was between 14 and 47. Findings do not distinguish between the ages of respondents, and the data extraction has tried to focus on only people over 18, though it is not possible to make this distinction always. Thirty-four participants were able to communicate, while 11 participants did not respond verbally or through a ‘recognised system’ (p296).

Analysis: Not reported.

Findings

Key findings: neither community care assessments as they stand, or IPPs, are universally successful in their aim of putting the individual in control. In addition, the outcomes of community care assessments are not delivered in a reliable or prompt manner. People with learning disabilities reported that their assessments were often difficult to interpret, disempowering and inaccessible. Furthermore, fewer than half of the services discussed at the assessment were provided one year later. However, carrying out a separate assessment of the carer’s needs was generally empowering, both to the carer and to the cared-for person.

Findings are reported under the following headings: i. Understanding the assessment process; ii. Understanding the IPPs; iii. Speaking up for one’s own needs; iv. Records of assessments; v. One year on; and vi. What the assessment process can achieve.

Understanding the assessment process

There was a lack of understanding shown by people with learning disabilities. Of the 19 participants who were asked about their community assessments, 4 people mentioned particular services or issues that their care manager had tried to solve and saw these issues as the purpose of the assessment

For one person, this was about moving out from the family home into a supported living situation:

‘It’s to go to another house... it’s part of his job to find a place’ (Study participant, p297).

Understanding the IPPs (Service review)

Twenty-five people were interviewed about their IPP – this is normally focused on the individual’s programme of activities. Many people with learning disabilities found the IPP system easier to understand, with 6 people expressing understanding of the forward planning function of their IPP, relating to their programme in the day centre:

‘It’s to do with my work.’

‘[It’s] to see what’s happening.’

‘They’re about my programme. The IPP is usually concerned with the individual’s programme of activities.’

Some comments suggested that individuals were not ‘in control’ of the process, but that others were controlling them, with the IPP often used as a means of monitoring their behaviour:

‘It’s to see how I’m getting on and not upsetting people’ (p298).

Only one person understood that it had a general function to help them plan for the future.

Speaking up for one’s own needs

The authors report that people with learning disabilities are not ‘used to being listened to, and perhaps lack skills and confidence’. One person recalls:

‘I try to say something, and then I forget what I’m going to say’ (Study participant, p299).

Twelve people reported to having private meetings with their social worker or key worker, and 10 reported feeling happy they had were listened to. One participant recalled their key worker helping them to look for paid employment:

‘She was helping me to speak up.’

At least 6 of 25 participants had not been present for their IPP, which supported previous research conducted by Carnaby (1997) who ‘raised concerns about the real involvement of people who do not communicate verbally’ (Author citation, p299).

Community care assessment

Of the 19 community care assessments conducted, 6 had a private meeting, whereas 3 participants reported that they had not been spoken to. One participant commented about the meeting with their care manager:

‘He didn’t sit down with me like you’re doing… he sat at the table with my mum.’

'Parents can easily dominate these situations, and the way in which the meeting is set up can be very influential. The carer may assume that s/he has to speak for the person, and the whole process can become focused on the carer’s views of what the individual needs' (Authors, p299).

Records of assessments – Community care

Authors report that assessments are not always meaningful to people with learning disabilities. One participant described their community care assessment:

‘It’s just a pile of paper with lots of squares – tick this, tick that’ (p301).

One individual who showed the researcher the record of his IPP said he could read. However, he was rather perplexed by the phrase:

‘Needs to participate more, verbally.’

Because of a lack of access to the printed record of assessment, many people depend on their carer to read the record to them. This makes it very hard for any kind of confidentiality to be maintained,

The IPP was reported to be more personal, and one participant's plan was personalised and accessible, containing unique 'strengths and needs, activities and goals… illustrated by means of photos that he had chosen and talked through with his keyworker' (Authors, p301). Successful features of the IPP are reported to include: accessible information; use of photos; getting-to-know-you-time; and enhanced communication (signing, symbols) (p300).

Considerations: This low (-) quality study is using an outdated assessment framework and legislation, originally the NHS and Community Care Act (1990), succeeded by the Care Act (2014). It is important to be mindful of interpreting findings because the sample age group is between 14 and 47, and the authors do not distinguish between each participant when reporting. Furthermore, it is impossible to ascertain if findings are representative geographically and across the service users' level of need. The authors are not clear about how each phase is reported in findings, some participants are only asked certain questions but the amount of participants who respond does not correlate with number of interviews conducted.

Evidence statements

The evidence statements were guided using the 6 'scoping framework' (refer to the review background document for GC5) higher order categories:

- Respect, dignity and control
- Personalised support
- Information and communication
- Active participation in lived experience of care
- Continuity of care and transitions (including access to care)
- Care and support for people's needs.

These themes are represented within the evidence statements that follow. The statements do not speak to individual themes; the statements often reflect several of the themes. Each statement is prefixed with the letters ‘LD' or 'LDV’ (learning disabilities studies or learning disabilities videos) respectively and a number, which is the statement’s numerical order in the list.

All evidence statements that follow are based on studies that are rich in direct user views.

Evidence statement measures

The evidence statements report two measures: amount and quality. The following conventions were used for amount of evidence:

- 1 to 2 studies - 'small amount'
- 3 to 4 studies - 'some evidence'
- 5 - 'moderate amount'
- 6 and above - 'good amount'.

In terms of quality, if more than 1 paper was used in an evidence statement, an average was taken of the weights assigned for each paper in order to provide an overall measure of quality for the evidence statement. For example, in a statement with 3 papers, if the first were rated medium (+), the second high (++) and the third low (-), the evidence statement would be recorded as ‘medium’ level quality. If 2 papers were scored high (++) and 1 medium (+), the evidence statement would be recorded as ‘high’ level quality. If there were an even number of studies of two quality levels (for example, two high and two medium), the evidence statement would be weighted on the lower side and recorded as ‘medium’ level quality.

Evidence statements from review of literature on views and experience of people with learning disabilities, including autism

LD1	**Staff shortages in services for people with learning disabilities** This evidence statement is based on some evidence of overall medium quality which found that staff shortages, and lack of support for staff results in no one being available to listen to resident complaints, or to provide regular and continued support more generally. People give high priority to being listened to and supported, and value regular contact with staff. In the first of 3 studies, (Hebblethwaite et al. 2007 −) investigated the experiences of people who had been homeless and were in contact with learning disability services. The second study (Miller et al. 2008 +) explored outcomes important to people with learning disabilities. The third study (Hoole and Morgan 2011 +) explored the lived

	experiences of people with learning disabilities as users of services. The studies found that staff shortages in supported accommodation and day care services for people with learning disabilities can lead to poor experiences of care.
LD2	**People with learning disabilities and homelessness** This evidence statement is based on a small amount of evidence of overall low quality, which found that people with learning disabilities expressed satisfaction with support to secure temporary accommodation, access counselling and develop life skills such as budgeting, cooking, shopping and filling forms. Some people valued volunteering as their main activity. In the first of two studies, (Hebblethwaite et al. 2007 −) investigated the experiences of people who had been homeless and were in contact with learning disability services. The second study (Miller et al. 2008 +) explored outcomes important to people with intellectual disabilities. The studies found that people with learning disabilities who had been homeless valued support provided by social care services.
LD3	**Activity and social contact for people with learning disabilities.** This evidence statement is based on one study of medium quality (Miller et al. 2008 +), which explored outcomes important to people with intellectual disabilities. This includes access to employment and volunteering, transportation, regular contact with staff, and feeling in control while living in supported accommodation. The study found that activity and social contact can make a significant contribution to the quality of life of people with learning disabilities.
LD4	**People with learning disabilities and disempowerment** This evidence statement is based on two studies, of overall medium quality. In the studies, some people highlighted that services should treat them equally, and give them the confidence to believe they had a legitimate right to services, which helps them feel valued and respected.. The first study (Hoole and Morgan 2011 +) explored the lived experiences of people with learning disabilities as users of services. This study further noted that people with learning disabilities felt empowered when they were given accessible information, access to self-advocacy forums and travel training. The second study (Miller et al. 2008 +) explored outcomes important to people with intellectual disabilities. The studies found that people with learning disabilities feel disempowered and not 'afforded the same rights' as people without a learning disability.
LD5	**Assessments for people with learning disabilities** This evidence statement is based on one study of low quality (Williams 2000 −), which explored the views of people with learning disabilities on their community care assessments and service reviews. The experience of one individual (level of disability unreported) suggested that care plans may be made more personalised and accessible if they incorporated different media, such as photos chosen by the individual and used with his or her keyworker. The study found that people with learning disabilities find their assessments are often difficult to understand, disempowering and inaccessible.
LD6	**Service user control in residential care,** This evidence statement is based on one study of medium quality (Miller et al. 2008 +), which explored outcomes important to people with intellectual disabilities. The research team reported that a large proportion of interviewees enjoyed having a variation in activities they can choose, but also the capacity to opt out if they wish. The study found that service users may have little control over their lives in residential care, and therefore place high value on the outcomes of choice and having a say.

LD7	**Independence, choice, mutual friendship and emotional support offered by Personal Assistants.** This evidence statement is based on one study of low quality (Norah Fry Research Centre 2010 −), which explored service users with learning disabilities and their experience of support received through social care. The study found that service users with learning disabilities value the independence, choice, mutual friendship and emotional support offered by their Personal Assistant.
LDV1	**Personalised care and behaviour that challenges** This evidence statement is based on a small amount of overall low quality evidence provided by two videos (SCIE 2012 −, SCIE 2014 −), which highlighted the importance of: • Interpreting behaviour that challenges as a manifestation of an unmet need. • Getting to know a person to understand what, for them, constitutes 'normal behaviour'. They described the importance of then paying close attention to the person, so any behaviour outside of this be an alert that the person is not happy or needs something. • Identifying what a person's triggers are and putting plans in place to avoid these, or to address them appropriately if they do happen. • Finding a way for the person to record their needs and preferences, and making sure that everyone involved in providing support can access this information. The videos found that personalised care can help to understand and respond to behaviour that challenges.
LDV2	**Control over personal budgets** This evidence statement is based on 1 video of low quality (SCIE 2009 −), which emphasised the importance of enabling the person (directly or by proxy) to identify how they want to spend their time and what makes them happy; and thinking creatively about how to use money available for support. The video found that there are demonstrated benefits of giving people control over their personal budget.
LDV3	**Supporting families of people with learning disabilities.** This evidence statement is based on a small amount of evidence of overall low quality from two videos (SCIE 2014a-, SCIE 2009 -). In one video, this related to people with learning disabilities, behaviour that challenges and communication needs. In another video, the person had a learning disability, epilepsy, communication needs and sensory impairment. Families need: Consistency of support, access to specialist support; training and advice on how to support the person; and access to respite and short breaks. The videos found it is important to support families of people with learning disabilities.
LDV4	**Inadequate support for people's sexuality and relationships.** This evidence statement is based on 1 video of low quality (SCIE 2010 −), which highlighted the importance of: not making assumptions about capacity to engage in relationships or sex based on a person's learning disability; and the need to support workers to find ways to support people's needs in relation to exploring and understanding their sexuality. The video found that there are negative impacts of inadequate support for people's sexuality and relationships.

Included studies

Gajewska U and Trigg R (2016) Centres for people with intellectual disabilities: Attendees' perceptions of benefit. Journal of Applied Research in Intellectual Disabilities 29: 587–91

Hebblethwaite A, Hames A, Donkin M et al. (2007) Investigating the experiences of people who have been homeless and are in contact with learning disability services. Learning Disability Review, 12: 25–34

Hoole Lucy and Morgan Sally (2011). 'It's only right that we get involved': service-user perspectives on involvement in learning disability services. British Journal of Learning Disabilities, 39: 5–10

Miller E, Cooper S, Cook A et al. (2008) Outcomes important to people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities, 5(3): 150–58

Norah Fry Research Centre (2010) 'It's all about respect': people with learning difficulties and personal assistants. Bristol: Norah Fry Research Centre: 17. Available at: http://www.scie-socialcareonline.org.uk/its-all-about-respect-people-with-learning-difficulties-and-personal-assistants/r/a11G00000017qgqIAA

SCIE (2009) Personalisation for Someone with a Learning Disability, rated poor (-) quality. Available at: http://www.scie.org.uk/socialcaretv/video-player.asp?guid=ed4aa862-69fe-4696-8422-a8a7e7c017be

SCIE (2010) Working With Lesbian, Gay, Bisexual and Transgendered People. People with learning disabilities. Available at: http://www.scie.org.uk/socialcaretv/video-player.asp?guid=c3f92700-3f9a-4b50-ab5e-13a70c952d73

SCIE (2009) Challenging behaviour and learning disabilities – independent living, rated poor (-) quality. Available at: http://www.scie.org.uk/socialcaretv/video-player.asp?guid=6db7a54b-0ba3-468f-95fb-4b823fab9bb6

SCIE (2012) Challenging behaviour and learning disabilities – improving services, rated poor (-) quality. Available at: http://www.scie.org.uk/socialcaretv/video-player.asp?guid=b4260f80-1b05-4a9e-9754-aa39efa2e9c8

Williams V and Robinson C (2000) 'Tick this, tick that': The views of people with learning disabilities on their assessments. Journal of Learning Disabilities, 4(4): 293–305.

3.5 Additional analysis: views and experiences of people who are hard of hearing, or with multiple sensory impairments

Introduction to the review question

This additional analysis formed a sub-set of the review work relating to review questions 1 to 3, with the specific purpose of exploring the views and experiences of people who are hard of hearing, or had multiple sensory impairments. This additional analysis was undertaken because the Guideline Committee identified this group as a group that may be at risk of poor care.

Review questions

1. Which aspects of the experience of using adult social care services are positive or valued by people who use services? (With specific reference to people with hearing difficulties or multiple sensory impairments.)

2. For people who use adult social care services, what are the barriers related to improving their experience of care? (With specific reference to people with hearing difficulties or multiple sensory impairments.)

3. For people who use adult social care services, what would help improve their experience of care? (With specific reference to people with hearing difficulties or multiple sensory impairments.)

Summary of the review protocol

Additional review question

Population

Adults who have a hearing or multiple sensory impairments aged 18 or over who use social care services.

Intervention

Experience of social care services.

Setting

All UK settings where care is delivered.

Outcomes: Qualitative themes – relevant to review questions 1 to 3

1. Wellbeing and quality of life (related to health, mental health and social wellbeing).
2. Engagement with services and care, including understanding relevant care and management issues where appropriate.
3. Choice and control.
4. Satisfaction of people who use services (including carer, family and advocate perceptions of how satisfied the people who use services are).
5. Perceived and objectively measured independence.
6. Ability to carry out activities of daily living with or without support.
7. Continuity of care.
8. Participation in social and community activities, including training and education, paid and unpaid employment.
9. Resource use
10. Security and personal safety.

How the literature was searched

The priority group studies relevant to this review question were a sub-set of those already identified for review questions 1 to 3.

We additionally searched databases that contained a range of relevant video evidence of people's experiences of social care. This included the Social Care Institute for Excellence (SCIE) Social Care TV and Think Local Act Personal (TLAP) video collection.

How the studies were selected

There was little high-quality research evidence in relation to this population, it was agreed to lower quality study designs for this question. All studies identified for review questions 1 to 3 were therefore re-screened using the lowered quality threshold, aiming to identify papers specific to people with a hearing impairment, or with multiple sensory impairments.

Following full text screening there were 3 studies that were specific to people with a hearing impairment, or with multiple sensory impairments. These were all qualitative studies, 2 rated as medium quality and 2 rated as poor quality.

Narrative summary of the evidence

Peace S, Katz J, Holland C et al. (2016) The needs and aspirations of older people with vision impairment: report for Thomas Pocklington Trust.

Review Question: 1

Methods: Interviews undertaken mostly in the person's home, or in an agreed 'public place'.

Data: Preferences for where and with what kinds of support older people with vision impairment would like to live. Central topics included a range of health, housing and social care issues. The study includes user views on accessing and using assistive technology.

Country: UK.

Setting: Not enough information is provided. Authors note that the study focus was people living mainly in mainstream community settings – including those living alone, living as couples, and a small number living with other family members (Authors, p58).

Scoping framework areas: Active participation in lived experience of care; care and support for people's needs.

Population group: Black and minority ethnic, older people, sensory impairments.

The primary aim of this medium (+) quality rated study was to facilitate older people with vision impairments living in community environments to express their preferences for where they would like to live and with what kinds of support they would like to live. The specific objectives of the research were to: understand choices over lifestyle and living arrangements; understand issues of personal identity; consider how control and autonomy can be maintained or delegated; address issues of risk-taking and responsibility.

Sample size: The study uses a purposive sample with a focus on respondents in late old age (over 85 years) and a range of eye conditions. Authors note that because of the shorter life expectancy of this population, a small number of people aged below 70 were included in the study. Additionally, a substantial number of the participants were aged under 85. Of the 50 older participants in the sample, 36 (72%) were women and 14 (28%) were men. Age range was 69 to 99 years: average 79 years; median 80 years. Forty-six (of the 50 participants) self-defined their ethnicities as follows: White British [including White English] 32; Black British 2; Asian British 2; European 2; Black African 2; Asian 5 [excluding Asian British but including Asian (3), Indian (1) and East African Asian (1)]; Mixed race 1.

Analysis: Seven interviews were carried out in ‘centres for the blind’. Interviewing at home was the preferred option as it allowed researchers to get a clearer understanding of the participant’s environment. Data analysis was undertaken via framework analysis (Spencer et al. 2003) using a template based on the original interview schedule covering topics including demographics, vision, health, housing and living arrangements, activities of daily living, and support. However, the authors do not elaborate on the process of data analysis.

Findings

Housing needs: Most participants lived alone, with the next largest group living with their spouse. Participants were asked if they had considered their future housing needs, and the possibility of living somewhere else. Other options such as moving to a bungalow, small flat, sheltered housing, extra care housing or residential care had either been rejected:

‘I hope and pray that I never have to go into a home – I know a very nice home, …I’ve been in there for respite a couple of times when my family had booked holidays…but its £800 or £900 a week and I have no property to sell. I can’t afford that. And there’s no way the council are going to pay that sort of money. And that’s the only place I’d really want to go, so I’m hoping I can manage’ (Participant, p24).

Home adaptations: Many participants were comfortable with their current accommodation. The research examined whether they had made any alterations or adaptations to make it more suitable for the vision impairment. Three kinds of alterations or improvements were described as follows:

1. Changes that householders make occasionally to make their home more comfortable, more spacious or more modern, for example refitting of kitchens and bathrooms. Such improvements did not benefit vision impairment, but contributed to general wellbeing and feeling of homeliness and control.

2. Adaptations concerned with physical impairments or ‘ageing’ generally:

Older participant:

‘[Occupational Therapist] suggested putting a rail up there, she said if my wife was going to be discharged…She put a grab rail by the bath. There was a handle at the top of the stairs, on the landing there, so when you got towards the top you’ve got something to hold onto to pull you up. What else did they do? Oh they put a half step outside the front door’ (Participant, p26).

3. Adaptations undertaken specifically for vision problems – these included the installation of wet rooms and shower rooms, especially downstairs; and indoor and outdoor guide rails. Some participants mentioned kitchen improvements such as

‘Better lighting, colour contrasts, and installing window blinds to reduce dazzle’ (Authors, p26).

‘Gaining advice about possible adaptions was hard to access and coupled with long waiting times for occupational therapy assessments or issues concerning funding. In a few cases, the local authority had funded adaptations, but more often they were self-funded or in some cases by a local sight loss charity. One participant described funding her own wet room after an OT decided she did not qualify for one. Another family converted an integral garage into a multi-purpose room so that the older person with vision and mobility problems would not have to go upstairs' (Authors, p27).

Assistive technology: The authors report that:

'Most interviewees were well versed about the latest types of aids and assistive technology available varying in sophistication and complexity. In many cases relatives or friends had scoured the internet looking for devices and priced them; sometimes participants had done this themselves or asked local vision organisations for advice. The most commonly used assistive devices were, in order of prevalence: various magnifiers (often several, in different rooms, and for image enhancement reader devices including Optelec); liquid level indicators; various labels and markers on domestic equipment; dedicated/specialised lighting; talking clocks; talking watches and computers with special large character keyboards. Several also used personal alarms and one with poor hearing a vibrating pillow fire alarm' (Authors, p27).

The authors go on to say that:

'Beyond these commonly used technologies, there were others used by fewer people. One person used a braille clock and watch and made her own braille diaries. 'Talking' devices and services included talking books/news (one using Gujarati services); microwave ovens; and talking phones, keyboards, calculators and kitchen scales' (Authors, p28).

Activities of daily living: The authors comment that:

'People described their activities of daily living (ADLs). How active they were related to their level of mobility, their vision, their feelings of wellbeing and how support was provided. Most participants were able to get in and out of chairs, wash themselves, put themselves to bed and go to the toilet. A small number (n=6) needed support to get in and out of bed and could not carry out basic washing or showering, or needed help at particular times' (Authors, p30).

For example, one participant says:

‘At night wife has to help me to go to the toilet’ (Participant, p30).

Regarding food preparation and eating, the husband of one prospective participant commented:

‘She is keen to talk about technology that helps her, she has got talking kitchen scales, a talking measuring jug, a talking alarm clock and a talking calculator. She has also devices to tell her when her cup is full, and when a pan is boiling’ (Participant, p32).

A vision friendly environment: The authors comment that:

‘Whether accompanied or unaccompanied, going outdoors and walking in the wider community could be problematic and may require using a stick. Nine participants used ordinary walking sticks whilst eighteen used white sticks. The ‘symbol cane’ is used additionally to alert others to the loss of vision and users need to have training’ (Authors, p34).

For example, one participant said:

‘The sight impairment team at the hospital put me in touch with the people who issue all this equipment. I asked for training for the long cane… and she explained to me how it works – I was taught how to use it and not to swish it around. I haven’t resorted to using it yet, but I wanted to get an idea of what it was like whilst I’d still had some eyesight to judge what she was saying’ (Participant, p34).

Another participant spoke about the barriers to pass the vetting system from the Guide dogs for the Blind:

‘I tell you it’s a real challenge for anybody who’s got sight problems to actually get through their system… you have to come up to a certain level of competence, intelligence I guess, to actually manage a dog like this’ (Participant, p36).

Formal support: The authors comment that:

‘Establishing how people initially found out about the formal support services they used was difficult as many participants could not remember. Relatively few recalled receiving home assessments from Occupational Therapists related to their vision loss at, or after diagnosis. A few did remember visits by social workers/care managers. A minority had home carers visiting daily helping them with personal care which were arranged through social services or independently. Several paid for cleaning services and/or help in the garden, from weekly to twice a year, depending on their needs and priorities. Many respondents were connected to organisations which provided support for specific types of vision impairment such as The Macular Society which focuses on a particular condition. The nature of this support varied, from advice to attending regular local support groups to hear talks from external speakers. For some respondents attending these meetings posed difficulties in terms of transport, with either practical or cost problems; but for many this was a lifeline and transport was organised through the members’ (Authors, p41).

The authors go on to comment that:

‘Generic vision impairment organisations (such as the Blind Veterans UK, Action for Blind People, RNIB, and local sight-loss groups) provided similar support as well as additional help such as holidays, trips to local attractions and meals out’ (Authors, p41).

The authors report that RNIB facilitated informal support among people with vision impairment, for example one participant enjoyed a mutual support network:

‘”Talk and Support”’ telephone connection: The RNIB connect six of us together on the phone every Thursday morning’ (Participant, p41).

The authors discuss that:

‘Where participants were not recruited through organisational networks they could feel very isolated as their contacts were limited to GPs and hospital clinics rather than support groups. These participants did not know how or who to challenge about changes in treatment for Macular degeneration. Other participants particularly from BAME groups were also unaware of the existence of organisations providing support for their specific sight impairment, although their pressure groups – as seen in

Coventry and Liverpool – would invite people from national groups (e.g. RNIB and Action for Blind People) and manufacturers to give talks and demonstrate products' (Authors, p43).

Considerations: This study seeks to understand preferences for where people with vision impairment would like to live and with what kinds of support, so it partly matches the review scope. Although the study examines the preferences of older people with vision impairment and what kinds of support they prefer, the reporting of social care issues was limited. User views are quite sparse overall. Much of the findings are based on author narrative. The conclusions are adequate, however, authors note that the study findings cannot be generalised to all older people with vision impairments as the study sample was accessed through organisations for people with vision impairment.

Think Local Act Personal (2010b) A Service user's personal budget story

Review Question: 1

Methods: Video evidence of service user views of using personal assistants (PAs) and personal budgets.

Country: UK.

Setting: Service user's own home.

Scoping framework areas: Respect, dignity and control; personalised support; active participation in lived experience of care.

Population group: Personal Assistants, Sensory impairment.

This overall low (−) quality study is a video of a service user who is profoundly deaf, describing how he lost confidence at the age of 16 when his eyesight started to deteriorate. He then started using his personal budget to help with his care.

Sample size: One single case study.

Analysis: Not research. Video transcript recording name of person speaking and what they are saying. Coded silver direct.

Findings

Key findings: The service user says he previously "had no confidence, my confidence was really, really low and I didn't have a lot of help or support."

He goes on to say:

"Now I have an individual budget and things are on the up for me, and things are really exciting – I've got PAs who help me and my life is much better. When I went to school it was a hearing school kind of in a mainstream school, there wasn't a lot of signing, just basic sign language I had when I was younger. Then I moved to high school, and there were around 30 to 40 deaf students there and they were using BSL, which I didn't really know about but I started to learn it and absorb it. When I became 16, and my eyesight started to deteriorate I was trying to communicate in sign language I was missing a lot of information – and a communicator came, he came and grabbed me wrists while he was signing. It's called hands on sign language and I understood from then on what I needed, I needed to change my BSL sign language to hands on sign language. So I'd like to have my hair cut today because I'm getting ready for tonight I'm going out in Manchester tonight with a lot of deaf friends, it's my girlfriends birthday tonight, and we're going to have a bit of a party in Manchester with all my friends tonight. I don't really feel deaf-blind myself – I feel just like a normal deaf person I feel very positive and with the hands sign language and the way I communicate and the way I'm guided, I'm quite happy with that…First of all, I had a direct payment, and with the direct payment everything was the same every week, you know, same hours same time, very restricting, you can't do that on a different day' (Service user participant, p1).

The service user describes how his personal assistant told him how he could use an individual budget to help him. He says:

"[PA] explained to me I'd need an individual budget and I'd need a reassessment which I had. I get to choose, the times, any time and also the people who work with me the personal assistants that gave me a lot of confidence I went out so much more" (Service user participant, p1).

The service user goes on to demonstrate how having a personal assistant has enabled him to undertake activities he wouldn't have been able to partake in previously:

“Regularly I go and watch football, with my PAs, also helps me to go clothes shopping, he’ll explain to me if I’m looking at some clothing, what it is what it looks like, the deaf club is what I enjoy the most. I meet all my friends there and we have a social life altogether and it’s a really good time for me. I can go out and do anything in my time, when I want to do it. I have a job as a lecturer for a company called Hear First, they’re a training company who run training courses for social workers. I talk to them about my life and I explain to them about individual budgets and direct payments and give them lecture to raise awareness for them to give them some idea how it affects deaf blind people, the feedbacks been really, really good. They say they’ve enjoyed it a lot, and gives me confidence” (Service user participant, p1).

Considerations: Not research or video conducted by researchers. Not enough background context provided to ascertain much about the context of the video participants or why they were invited to take part in providing this evidence.

Ward L, Banks L (2017) Older people’s experiences of sight loss in care homes.

Review Question: 1

Methods: Qualitative, Semi-structured interviews.

Data: Views and experiences of older people in residential care homes who have experienced sight loss. Thirteen women, 8 men, aged 63 to 98 years.

Country: England.

Setting: Residential care homes, mainly in London boroughs.

Scoping framework areas: Personalised support; active participation in lived experience of care; care and support for people’s needs.

Population group: Sensory impairment.

This overall medium (+) quality study aims to address gaps in evidence by interviewing older care home residents with sight loss and exploring the perspectives of their relatives and care staff. In particular, it explores how daily routines and the physical environment of the setting contribute (or not) to wellbeing for residents with sight loss, which aspects of practices within the setting are valued and considered helpful, and how relationships can support living well with sight loss within residential care.

Sample size: Twenty-one care home residents who were aged between 63 and 98, 13 were women and 8 were men. Ten members of care home staff. Nine relatives of care home residents.

Analysis: No details of the methods of data collections were described, but data was said to be transcribed verbatim and thematic analysis undertaken, an Experts by Experience panel was involved in the development of interview questions, and advised on ethical considerations and the analysis and interpretation of findings.

Findings

Facilitators

Awareness of sight loss among staff, particularly agency staff. Awareness was also appreciated from other residents.

Adequate staffing levels and staff time to provide emotional and social support. Residents talked about wanting more time to just talk with staff and highlighted the importance of having company.

There was a need for support for new residents to become familiar with the care home and negotiate the care home environment.

The importance of volunteers to help engage in activities and go out, but difficulty in accessing volunteers.

The importance of friendships, company and conversation, but social interactions can require facilitation by staff.

‘They’re very, very good to me, they’re very helpful. I mean they tell me every, you know, even to sitting down, turning round and sitting down and making sure that I’m, I don’t fall, you know, they’ve been very good. … I mean like the nurses and the staff here, they, well, they, they’re like friends, they’re very good to me and I don’t think they’ve been able to have done so much, because they have been good, they have been good, and been very patient, so they put themselves out, they’re very, they’re very good’ (Participant, p30).

‘You can only say nothing but praise of them, they were unfailingly kind and polite and nice and helpful but they’re pushed lately, I mean they’re rushing around like I don’t know what. They’re all nice, I mean you know, the carers, they are all nice, I mean they don’t sit down for half an hour to chat but I chat. They chat and then they go, excuse me, I must get on, which is fair enough but they are good’ (Participant, p30).

A reliance on family and friends to provide support leads to difficulties when help from family and friends is not available.

The sense of loss related to sight loss and loss of activity, depression and lack of emotional support. Relationships with others are crucial in counteracting feelings of isolation.

‘I like company, I’m not much good in my own company and here, I’ve been here two and a half years and the first year was really quite dreadful because there was very few people, not many people here and fewer still who’ve properly got their wits about them. I don’t mean to sound awful but I mean there was no one to talk to, properly talk, you know. So it was miserable, miserable, miserable’ (Participant, p31).

The added financial costs related to sight loss, for example, transport and equipment. Difficulties with accessing or finding out about equipment, which might help to address the issues of living with sight loss.

Barriers

Insufficient support from outside, especially lack of input from rehabilitation workers and lack of perceived support associated with registration.

‘…well it’s difficult to say anything about my sight without grumbling and I don’t, I’m not a grumbler, I sort of accept things as they are’ (Participant, p25).

More knowledge is needed of aids and adaptions, and technology that could help residents to maintain their interests or develop new ones.

‘Well it’s all on one level, isn’t it? If I go out that door and turn left, I’m in the, in where they serve the food up, you see, and if I go further in, it’s a lounge, like, a sun lounge, windows all the way round and, you know, and televisions and record players and God knows what else. I’ve got no difficulty at all. If I went outside, I’d like to hold onto somebody or something that’s firm’ (Participant, p38).

‘There is an awful lot of things that I cannot do. I do try, I go down to the craft and I have a go but that I find very frustrating because I was so good at anything with my hands and now I can only feel and I don’t know if I’ve done it right, you know, but I do have a go’ (Participant, p43).

‘You feel, when you’ve had an active life you feel terribly frustrated that you can’t see to do things, you can’t use your brain’ (Participant, p43).

‘”So you don’t really join in with activities?” Interviewer “One or two but not many because I can’t do it properly and it upsets me”’ (Participant, p43).

Better connections are needed with local external organisations such as sight loss societies and rehabilitation services.

‘They say would you like a volunteer and you say yes and you forget all about it and then about eighteen months later! But it’s a question of finding someone they think you’ll, you know, match with and I’ve got an extremely good volunteer who comes, well when I ask her to, to sort of do a few odd jobs for me here and then, weather permitting, go out and have coffee or something’ (Participant, p34).

Considerations:

It was not clear what methods of data collection were used, for example if there were any adaptions made for individual participants to assist in taking part in interviews, where the interviews were held, methods obtaining informed consent, and maintaining confidentiality in a communal setting. Only care homes meeting all standards in the most recent assessment (307 care homes and 363 nursing homes) were selected (that is, functioning well). However the aim of the research was to identify good practice rather than barriers to good care. All but one of the care homes were in London boroughs and this is out of 14,503 registered care homes in England. The majority of Care Quality Commission inspections of care homes report either good or needs improvement. Although barriers to good care were identified, the care homes were already selected for providing good quality care based on Care Quality Commission inspection report, so it is may be that the whole range of barriers to good care experienced by older people in care homers with sight loss are not identified from this sample, hence the recommendations only apply to improving quality of care in already high performing care homes. Themes were developed from older people and their families, and members of staff of care homes, and it is not always clear from which perspectives the themes were developed.

Evidence statements

The evidence statements were guided using the 6 ‘scoping framework’ (refer to the review background document for GC5) higher order categories:

- Respect, dignity and control
- Personalised support
- Information and communication
- Active participation in lived experience of care
- Continuity of care and transitions (including access to care)
- Care and support for people’s needs.

These themes are represented within the evidence statement that follows. The statement does not speak to individual themes; the statement reflects several of the themes. The statement is prefixed with the letter ‘V’ (which stand for Views studies) and a number.

All evidence statements that follow are based on studies that are rich in direct user views.

Evidence statement measures

The evidence statements report two measures: amount and quality. The following conventions were used for amount of evidence:

- 1 to 2 studies - 'small amount'
- 3 to 4 studies - 'some evidence'
- 5 - 'moderate amount'
- 6 and above - 'good amount'.

In terms of quality, if more than 1 paper was used in an evidence statement, an average was taken of the weights assigned for each paper in order to provide an overall measure of quality for the evidence statement. For example, in a statement with 3 papers, if the first were rated medium (+), the second high (++) and the third low (-), the evidence statement would be recorded as ‘medium’ level quality. If 2 papers were scored high (++) and 1 medium (+), the evidence statement would be recorded as ‘high’ level quality. If there were an even number of studies of two quality levels (for example, two high and two medium), the evidence statement would be weighted on the lower side and recorded as ‘medium’ level quality.

Evidence statement from review of literature on views and experiences of people who are hard of hearing, or with multiple sensory impairments

V9	**Information about services** This evidence statement is based on a good amount of evidence of overall medium level quality. In the first of 8 studies, (Barnes and Mercer 2006 ++) discussed users' experiences using mainstream, community-based support services and how this contrasted with disabled people's experiences of user-led services. The second study (Cameron et al. 2016 +) tracked a group of homeless women/ at risk of homelessness to determine how their service needs (including social care needs) changed over this time. The third study (Katz et al. 2011 +) examined the views of what older people with high support needs valued in their lives, and within services. The fourth study (Abbott et al. 2000 +) explored the views and experiences of adults living in sheltered housing or residential care settings. The fifth study (Stewart et al. 2011 +) examined older people’s experiences of living with falls at home. The sixth study (Beech et al. 2013 ++) examined care received before, during and after a health crisis. In the seventh study, (Peace et al. 2016 +) explored preferences for where and with what kinds of support older people with vision impairments would like to live. The eighth study (Ward and Banks 2017 +) looked at the views and experiences of older people in residential care homes who had experienced sight loss. The studies found that information about services is lacking, inaccessible, sub-standard or inconsistent, especially when

	accessing follow-on care. This is particularly problematic for people with newly acquired impairments or multiple sensory impairments.

Included studies

Peace S, Katz J, Holland C et al. (2016) The needs and aspirations of older people with vision impairment: report for Thomas Pocklington Trust. Milton Keynes: Open University. Faculty of Health and Social Care.

Think Local Act Personal (2010) A service user's personal budget story. Video transcript. London: TLAP.

Ward L and Banks L (2017) Older people’s experiences of sight loss in care homes. Brighton: Social Science and Policy Research Centre.

3.6 Additional analysis: views and experiences of people who employ Personal Assistants

Introduction to the review question

The Guideline Committee identified people who employed personal assistants as underrepresented in the research literature. They therefore suggested there should be a particular focus on people's views and experiences of employing personal assistants, separate from more general views and experiences of social care. An expert witness was also invited to speak on this topic.

Review questions

1. Which aspects of the experience of using adult social care services are positive or valued by people who use services? (With specific reference to people who employ personal assistants.)

2. For people who use adult social care services, what are the barriers related to improving their experience of care? (With specific reference to people who employ personal assistants.)

3. For people who use adult social care services, what would help improve their experience of care? (With specific reference to people who employ personal assistants.)

Summary of the review protocol

Additional review question

Population

Adults who use personal assistants aged 18 or over who use social care services.

Intervention

Experience of social care services.

Setting

All UK settings where care is delivered.

Outcomes: Qualitative themes – relevant to review questions 1 to 3

1. Wellbeing and quality of life (related to health, mental health and social wellbeing).
2. Engagement with services and care, including understanding relevant care and management issues where appropriate.
3. Choice and control.
4. Satisfaction of people who use services (including carer, family and advocate perceptions of how satisfied the people who use services are).
5. Perceived and objectively measured independence.
6. Ability to carry out activities of daily living with or without support.
7. Continuity of care.
8. Participation in social and community activities, including training and education, paid and unpaid employment.
9. Resource use
10. Security and personal safety.

How the literature was searched

The priority group studies relevant to this review question were a sub-set of those already identified for review questions 1 to 3.

We additionally searched databases that contained a range of relevant video evidence of people's experiences of social care. This included the Social Care Institute for Excellence (SCIE) Social Care TV and Think Local Act Personal (TLAP) video collection.

How the studies were selected

There were 8 studies and 1 unpublished study that described people's views and experience of using personal assistants and was identified from the map of key characteristics of studies.

Two studies were of medium quality, 7 studies were assessed as being low quality.

Narrative summary of the evidence

Abbot et al. (2017). Lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI+) disabled people and self-directed social care support in England

Methods: This is a mixed methods study which consists of a survey of 56 LGBTQI+ disabled adults; qualitative interviews with 20 LGBTQI+ disabled adults drawn from the survey sample; and a focus group of Personal Assistants (PAs).

Data: Views and experiences of LGBTQI+ disabled men and women using self-directed social care support.

Country: England.

Setting: Not specified, but assumed to be people's own homes and locations where social care is received.

Scoping framework areas: Respect, dignity and control; Personalised support; Active participation in lived experience of care; Care and support for people's needs.

This study, rated overall medium (+) quality has the following aims and objectives:

'1. Understand more about the specific social care needs of LGBTQI+ Disabled people and how they are, or could be, supported by adult social care professionals through self-directed social care.

2. Improve social care professionals’ understanding of and approaches to the social care needs of LGBTQI+ Disabled people thereby improving outcomes for service users.

3. Gain insight from support workers and personal assistants (PAs) of potentially helpful and empowering ways of supporting and interacting with LGBTQI+ Disabled social care recipients and overcoming challenges or barriers'. (Authors: page 2).

Sample size: 56 LGBTQI+ disabled adults, of whom 53% identified as female, 30% as male and 15% as non-binary. In terms of sexual orientation, individuals described themselves as follows: 34% lesbian/gay woman; 26% a gay man; 32% bisexual; and 20% identified as trans. 53 individuals described themselves as White, one as Indian, one as White and Asian and one individual's details were unreported. Age was also unreported.

Analysis: No detail was provided in the final published study on the methods used to analyse the data.

Findings

Key findings:

The findings highlighted that more than half of the survey respondents said that they never or only sometimes revealed their sexual orientation or gender identity to their PAs. Less than one third said that they were 'very comfortable' discussing their support needs regarding being LGBTQI+ with their PAs.

The authors note that: ‘There was a full range of being out to PAs: not out, out to some and out to all. Some that were out or out to all talked about how pleasurable and important it was to be open about their sexuality or being trans. Some interviewees said that they were not immediately out to PAs but adopted a "wait and see" policy’. (Authors: page 2).

Several people said they were unhappily resigned to the idea of not being fully out because of their anxiety about the reaction of the PA and the implications on their care and support:

“I have the bloody right to be who I am in my own home. You know, if I can't be myself in my own house, I'm really screwed, you know. Because I need people working for me who can handle queers coming in and out of the house, who can handle maybe that one of my friends who used to be a girl is now a guy this week, who can handle going out to protests with me, who can handle turning up at LGBTQI+ events with me, you know.” (Study participant: page 2)

“If I fire someone I've got to have an alternative before I can do that. You can't just find people in two or three hours. It's meant I've had to put up with more bad behaviour if I hadn't had to think, 'Well what's the alternative?'” (Study participant: page 2)

Over a third said that they had faced discrimination or had poor treatment from their PAs because of their sexual orientation or gender identity.

Most interviewees talked about difficult experiences with PAs and other social care staff regarding their package of support, at times discriminatory, even abusive. Agencies were seen as slow to respond.

Some interviewees were very discreet at home:

“If I had a copy of 'Gay Times' I would probably make an effort to make sure it wasn't there... especially when you've got a new carer coming in... just in case they're homophobic.” (Study participant: page 3).

Over 90% of study participants said that their needs as a LGBTQI+ Disabled Person were either overlooked or only partly considered during assessment or review. Less than a third said they felt at ease talking about these needs with staff in their local authority. Assessments did not consider the whole person, by ignoring sexual orientation or gender identity.

One person describing the process of filling in an assessment form, said:

“I picked it up, signed it and wrote the date in the box, and I said to her, [social worker] 'Oh, what's this?' And there was a box about my sexuality, and she had not asked me. And I said, 'Oh, what's this bit? You haven't filled it.' She said, 'Oh, I never bother with that. I don't think it's really relevant.' But actually it's important that we are represented within these things, and that people know that trans people and queer people are being seen. I just said to her, 'Well I'm going to fill it in.' It felt a bit too much like sweeping it under the carpet. And I don't want to be swept under the carpet.” (Study participant: page 4).

Some people were worried that being too open may negatively affect the outcome of assessments:

“I do worry if a care manager was very religious or whatever that they may not give me a totally fair assessment if they're judging my life or lifestyle.” (Study participant: page 4).

In terms of being supported to do LGBTQI+ 'things' (e.g. go to an event/bar, support to maintain friendships and relationships), 22% said that their PAs did not assist them. When asked further, 40% said it was because they were not out to their PAs; 40% said they were uncomfortable with their PAs supporting this; and 20% said that their PAs had declined to help with such activities.

There were also positive examples cited by study participants:

“My PA was delighted to come on Pride with me. My PAs, I'm very open with them about my work, my lifestyle, about my orientation and about my gender. I need people to work with me that respect my independence and who are happy to see me participating in my community doing things that enrich me. I need my PA to come to Pride and go with the flow and not care that some man may come and kiss him on the cheek. My PA enjoyed Pride, he was glad to go.” (Study participant: page 4).

Many people expressed the desire for more LGBTQI+ PAs.

In the qualitative interviews and survey, people described the benefits and challenges of self-directed social care support.

Having control over support arrangements was the most frequently mentioned reason for a preference for self-directed support. Previous experiences with agency workers were negative:

“You have different people all the time, you've got strangers coming into your house. I wanted to be able to choose. It's transformative if you get the right person.” (Study participant: page 4).

Most of the interviewees expressed a desire to have more support for 'social hours' to reduce isolation.

A repeated theme in the research was the difficulty of recruiting and retaining good quality PAs. The reasons included a lack of guidance and support with recruitment processes and a lack of support and information about dealing with disagreement or conflict within support relationships/arrangements.

Considerations: Certain aspects of the methodology were not reported in detail. For instance, there is little detail about what questions were asked of respondents for each element of the research, details of how data were analysed, and limitations in terms of potential researcher bias. On the basis of what information has been provided therefore, the study has been rated medium quality (+).

IFF Research (2008) Employment aspects and workforce implications of direct payments: research report.

Review Question: 1

Methods: 526 face-to-face interviews with Direct Payment employers in 16 Local Authority areas.

Data: The employment aspects and workforce implications of the Direct Payments scheme. The survey questions focused largely on the person or persons employed through Direct Payments, and these individuals were not present during the interview.

Country: UK.

Setting: Interviews were conducted either in the person's home or at a convenient location and with the employer alone, or where requested by the employer, with a representative or support person present.

Scoping framework areas: Respect, dignity and control; personalised support; active participation in lived experience of care; continuity of care and transitions; care and support for people's needs.

Population group: Personal Assistants.

This is the first ever large-scale study rated medium (+) quality of recipients of direct payments in their role as employers. The study was carried out in three phases using quantitative methods: of a main employer survey (526 face-to-face interviews with Direct Payment employers in 16 Local Authority areas), self-completion survey of Personal Assistants (PAs) and a telephone survey of PAs (100 individuals who had completed the self-completion survey).

Sample size: 'A total of 526 Direct Payments (DP) employers were sampled from across 16 participating Local Authorities, representing 7% of the total population of 7,539 individuals in receipt of Direct Payments in these areas, and 1% of the total number of employers nationwide (54,151)' (Authors, p13). From the sample of 526, there was an even spread of employers of different ages. One hundred and fourteen were older people. Employers were divided into 6 groups where older people comprised the largest proportion (29%), followed by carers (27%), and employers with a physical disability or long-term illness (27%). Employers with learning disabilities and those with sensory impairments or mental health issues made up 12%, 2% and 3% respectively.

Analysis: No detail is provided on this.

Findings

This narrative summary is based on reported findings from the first phase of this research. These findings focus on qualitative data from the main employer survey, carried out between February and November 2007. This was based on the findings of the Sheffield/New Types of Worker research and other key published research, and developed in consultation with the project steering group. The findings are presented under key themes.

General satisfaction: The authors report that employer satisfaction with the personal assistants employed through Direct Payments was very high – 8 in 10 rated themselves as 'very satisfied'. Those employers who were receiving support administered by their Local Authority before receiving direct payments (48%) expressed dissatisfaction with these services, for example, support worker's ability to carry out household tasks and their punctuality and general reliability (compared to only 8% of all employers dissatisfied with their current personal assistants (Authors, p28).

Abuse: Over one in ten employers who have accessed support through their Local Authority in the past have experienced psychological abuse from their support worker (13%), most commonly related to the support worker undermining or belittling them, excluding or ignoring them, or insulting them. Such abuse was reported much less by employers using Direct Payments to employ someone.

Reliance on family/friends: The most common benefit expressed by employers was a reduction on the reliance on family and friends by employers and existing carers (21%). Example comments included:

'It has stopped me having to rely on my mum and dad. I can ask my Personal Assistant to do things that I would not like asking my parents to do. I feel more independent and it's less worrying not having to rely on my parents' (Participant, p42).

'It has made a huge difference to me and my wife as the people responsible... It means we can go out to the theatre or on holiday without relying on family and friends' (Participant, p42).

'It has made a great difference. It has taken a lot of weight off my husband who is not well himself – he has a bad back. The tasks the Personal Assistants do, he does not know what to do' (Participant, p42).

Independence and control: 14% described how receiving Direct Payments has led to them gaining or re-claiming their independence, and the same number (14%) stated that the scheme has allowed them to gain more control over their lives and to make their own decisions:

'It means you are more in control, even if it is a bit of a headache sometimes' (Participant, p43).

'It has given me freedom. I can now get out and about when I want to rather than waiting around for someone to help' (Participant, p43).

'Without Direct Payments, I would not be able to hold down a full-time job and live my life so independently. I am in control’ (Participant, p43).

'It means I am now free. It is a lot more flexible and it means I can chop and change what I want to do daily' (Participant, p43).

Consistency: One in seven employers (15%) said that the scheme had changed the way they are cared for as they can now employ the same personal assistant on a consistent basis, with whom they can build a more personal and trusting relationship:

'It has given me the ability to choose the person who is looking after me. I am a very private person. Now rather than having different people in every day, I have a person who knows me and what I am capable of doing' (Participant, p43).

'It has allowed me to have continuity of care. This means that the Personal Assistant knows how to deal with them [the employer], she knows what food they can eat and she has got free run of the house and I trust her' (Participant, p44).

Financial remuneration for family and friends: 2% reported specifically that Direct Payment has allowed them to employ a family member or other personal friend who would not previously have received any financial support for caring for them:

'It makes me happier that someone is now getting paid to do the jobs, like showering me. I think it is a job that someone should get paid to do. It has given me more control over my life' (Participant, p44).

Improved standard of care: 12% employers and their representatives feel that the introduction of Direct Payment has led to them getting a better standard of care:

'My carers are marvelous. More like a friend than doing a job, more like a friend or neighbour's attitude. My cleaner does extra jobs that were not done before. The Personal Assistants do certain tasks that they would not do in regular hours. I do not have to keep telling them what to do' (Participant, p44).

Consistency of support (15% of employers) and choice (13% of employers) has made a considerable change to the way care was provided:

'It has given me the ability to choose the person who is looking after me. I am a very private person. Now rather than having different people in every day, I have a person who knows me’ (Participant, p43).

Barriers – A number of barriers were reported:

Admin and paperwork pose a lot of problems.

'Being an employer and doing the PAYE and all the paperwork. It's very daunting' (Participant, p45).

'The big thick instructional book frightened me...' (Participant, p45).

One in ten employers with concerns reported specifically that they find dealing with personal assistant payroll and tax administration problematic.

'The only concern is that I was not writing down everything, e.g. everything that gets spent. They did not tell me you had to fill in forms and are audited every year. I was not told that you could pay for the Personal Assistant holiday carer. The paperwork is too much' (Participant, p46).

Three per cent of employers noted that they feel those issuing Direct Payments are disorganised, and a further 3% reporting that they feel that they do not communicate well with employers:

'There is a lack of communication and understanding. There are problems with the collaboration between the DP and the ILF. Employing a number of PAs, this increases amount of paperwork and auditing. I sometimes feel there should be more support in this process' (Participant, p46).

'There have been difficulties in hiring staff due to the numbers of hours allotted. i.e. 1 hour in the morning, 2 hours in the afternoon. Potential staff want more hours than I can give them to make it worth their while working' (Participant, p47).

Money: 'My only concern relates to the fact that I am not getting enough money to cover each month. I really need someone to come in every day, rather than no one being here on Tuesday and Friday as happens at the moment' (Participant, p47).

One fifth of employers cited poor transport links:

'People need a car to drive here, as it is a very rural area...' (Participant, p57).

Considerations: Questionnaires were piloted extensively involving two phases. Data was collected for the whole research using more than one method. However, there is no sufficient reporting of the methods of analysis. The study has not mentioned any information in relation to gaining ethical approval or ethical issues more broadly.

Norah Fry Research Centre (2010) 'It's all about respect': people with learning difficulties and personal assistants.

See narrative summary in section 3.4.

Social Care Institute for Excellence (2014b) Dignity in Care – Privacy.

The video and transcript are available at: http://www.scie.org.uk/socialcaretv/video-player.asp?v=privacy

Methods: This is an illustrative case study and not a primary research study. There is no stated methodology. However, the video does feature scenarios from the life of people with social care needs and those that support them. The video focuses on areas relevant to our review questions on (RQ1) improving experience, and on (RQ2+3) barriers and facilitators.

The overall quality rating is low (−) quality: the video features rich, relevant experience data, but it includes only a small number of participants and settings and no methodological details.

Data: Qualitative self-report data.

Country: England.

Setting: The video references support provided by personal assistants, and more generally to support provided in residential care settings.

Scoping framework areas: Respect, dignity and control.

Population group: Personal Assistants.

Sample size: The video features people who use services, personal assistants and care managers.

Analysis: This is an illustrative case study and not a primary research study. No description of analysis is provided.

Findings

A key message is that "privacy is a fundamental aspect of maintaining dignity" (Narrator, p1) and people have a right to this across a range of areas of their life: their home, their post, their relationships, using the bathroom, their personal information.

Workers and managers emphasise that the default position, irrespective of where someone is supported, is to respect their privacy. This means, for example:

- asking explicit permission before going into someone's room
- asking someone what support they want
- providing the minimum intrusion and maximum privacy with whatever support is provided, for example, even if someone needs support to get onto the toilet, the worker can still give them privacy when they use the toilet
- sharing information on a 'need to know' basis.

A personal assistant describes how people open and check their own post, and then ask for any support or actions to be undertaken as a result of what is in their post.

Considerations: The video aims to provide an illustrative example, however, it should be interpreted with caution given the limitations in terms of methodology and sample described above.

Think Local Act Personal (2010a) A service user's personal budget story

Review Question: 1

Methods: Qualitative video interview study of people's experience of social care.

Data: Transcripts from video interview.

Country: UK.

Setting: Service user's own home.

Scoping framework areas: Respect, dignity and control; personalised support.

Population group: Personal Assistants.

This overall low (−) quality study is a video about views and opinions of using 'self-directed support' and using personal assistants, which meets the scope criteria.

Sample size: One single case study.

Analysis: Video transcript recording of a male service user speaking and what they are saying. Coded silver direct.

Findings

A service user discusses the benefits of having direct payments. He describes having this kind of social support as being very positive. He says SDS (self-directed support): '[direct payments] has enabled me to employ a personal assistant OK. Because I only have one arm that normally works ok I can't open a letter, or a bottle and my PA comes first thing in the morning I employ her to arrive at 9ish in the morning, ok, and stay until lunchtime, that's it, that's 5 morning a week which is what I ask her to do and she'll work for that time, which is brilliant – so with my SDS (Self Directed Support). I buy that 'cause that's what I need'(Service user participant, p1).

He goes on to say:

'I’ve got another bedroom now, so in the future if it works out I could have a live in carer now. I would say first of all not to be frightened of what might seem a great bit step, but it’s a step in the right direction, believe you me it is. Some people are going to be daunted by going to this whole thing of SDS (self-directed support), you know being this age, and disabled, and being this age and getting a mortgage right? Not easy – and start a little company going and employing one or two people – all that is fairly daunting for most people, but in fact there’s help out there to help you there are people around to guide you through all that and I used them and it was easy, easy peasy'(Service user participant, p1).

Considerations: Not research or video conducted by researchers. Not enough background context provided to ascertain much about the context of the video participants or why they were invited to take part in providing this evidence.

Think Local Act Personal (2012a) Making it Real

Review Question: 1

Methods: Qualitative video interview study of people's experience of social care.

Data: Transcripts from video interview.

Country: UK.

Setting: Service user’s own home.

Scoping framework areas: Respect, dignity and control; personalised support.

Population group: Personal Assistants, People with a disability.

This overall low (−) quality study is a video about views and opinions of using individual budgets and using personal assistants, which meets the scope criteria.

Sample size: One single case study.

Analysis: Video transcript recording name of person speaking and what they are saying. Coded silver direct.

Findings

Key findings: a male service user with HIV portrays a positive picture of how having control over his personal budget he can meet his personal needs well and remove the stigma that might have occurred had he not been in control over whom to employ. His description of his care suggests consistency of having the same person care for him is also an advantage to him.

He says: 'When you use an individual budget and you have real control, you design it, you own it, you feel responsible for it. You want people to come on board that have the same values and aspirations. I've chosen to employ a gay man as a PA because I don't have to explain anything around my sexuality, I don't feel embarrassed to talk about my HIV. I don't feel uncomfortable if I decided to have a relationship, I don't need to feel anything at all other than that I feel supported. I feel that my care is a really positive thing for myself and I feel very happy with it because I'm in control, I'm able to decide what type of care I need and it can vary. I'm actually able to employ different people to do different things or employ the same person to do the same thing and I'm able to use one person to work in many different areas of my life. I share my PA with another disabled person, the turnover isn't so high so my PAs been with me for a year. We want to keep somebody that really works hard and is able to work in that social model of disability rather than us being products. For me to be pro-active and for to be the person I what to be in society, I may need a little bit of support but I feel that having that support and for me to own that support and for me to direct that support is really positive progress'(Service user participant, p1).

Considerations: Not research or video conducted by researchers. Not enough background context provided to ascertain much about the context of the video participants or why they were invited to take part in providing this evidence.

Think Local Act Personal (2012b) Making it Real. A woman with Alzheimer's

Review Question: 1

Methods: Qualitative video interview study of people's experience of social care.

Data: Transcripts from video interview.

Country: UK.

Setting: Service user’s own home.

Scoping framework areas: Respect, dignity and control; personalised support.

Population group: Personal Assistants.

This overall low (−) quality study is a video about views and opinions of using individual budgets and using personal assistants which meets the scope criteria.

Sample size: One single case study of a woman with Alzheimer's.

Analysis: Video transcript recording of a woman with Alzheimer's speaking and what they are saying. Coded silver direct.

Findings

Key findings: The woman describes the positives of having a personal assistant and the independence this gives her to make her own decisions and get involved in activities that would be restrictive otherwise.

She says: 'I've got Alzheimer’s and I would never like to be on my own – you know, I love company, I like to have conversation and you know, people that are nice to me. I've got a carer, which is G and she's very good, she's fantastic, very reliable and she looks after me very well and very caring, which I like. I've known G many years but very capable person she is. She helps me indoors and we go out. I go to Age concern, places like that. We go to bowling, I love bowling - it's great fun. And I've got a sheet, you know, what we can do daily. I can make my own decisions and how I feel, then I explain that. Monday I have M - just one day and then G comes and after that my children come so it's all slotted in. I'm very lucky to have such good people around me'. (Service user participant, p1).

Considerations: Not research or video conducted by researchers. Not enough background context provided to ascertain much about the context of the video participants or why they were invited to take part in providing this evidence.

Think Local Act Personal (2009) A service user's personal budgets story

Review Question: 1

Methods: Qualitative video interview study of people's experience of social care.

Data: Transcripts from video interview.

Country: UK.

Setting: Service user’s own home.

Scoping framework areas: Respect, dignity and control; personalised support, active participation in lived experience of care.

Population group: Personal Assistants.

This overall low (−) quality study is a video about views and opinions of using direct care payments and using personal assistants, which meets the scope criteria.

Sample size: One single case study.

Analysis: Video transcript recording of a service user speaking and what they are saying. Coded silver direct.

Findings

Key findings: the service user describes the positives of using her personal budget to employ a personal assistant and the independence this gives her to make her own decisions and get involved in activities that would be restrictive otherwise.

She says:

'I didn’t want someone to be able to say to me "You can’t do that" or "You can’t do that". I wanted to be able to set a programme up so I could have what I needed when I needed it. My aims are to be able to access the community, meet my friends, be with family. Personal Budgets make it very easy for you to do that. I’m not able to go to see my family because they are, they live in houses that are totally inaccessible to me. What I can do is pay for a hotel room in London and then have my PA come along with me and she helps me while I’m in the hotel, I don’t have to rely on a member of my family. I have in the past had to stay in nursing homes because I can’t visit a hotel because the care hasn’t been there for me. It’s changed everything. I’ve been able to go places, do things, even the simple things like just going to the pictures has been a great change to my life and it's made getting up in the morning a positive thing rather than "Oh, not another day dragging on for another 12 hours" ' (Service user participant, p1).

She goes on to say:

'Getting to know what I had to do as an employer, it wasn't that difficult at all. You can have someone to help you do your wages, I chose to do my own and do my own accounting but people can have agencies or another agency to help them with their payments. And 'Personal Budgets can help you to be independent, it can help you to live alone and live your life as an independent person. The freedom to choose, it's what's really brilliant about it, being able to choose when and where, who and why and it takes away the control from somebody else saying "You can't do that and you can't do this", so it's brilliant' (Service user participant, p1).

Considerations: Not research or video conducted by researchers. There was not enough background context provided to ascertain much about the context of the video participants or why they were invited to take part in providing this evidence.

Think Local Act Personal (2010b) A service user's personal budget story

See narrative summary in Section 3.5.

Evidence statements

The evidence statements were guided using the 6 'scoping framework' (refer to the review background document for GC5) higher order categories:

- Respect, dignity and control
- Personalised support
- Information and communication
- Active participation in lived experience of care
- Continuity of care and transitions (including access to care)
- Care and support for people's needs.

These themes are represented within the evidence statements that follow. The statements do not speak to individual themes; the statements often reflect several of the themes. Each statement is prefixed with the letter 'TLAPV' (which stands for

TLAP Views videos) or V (which stands for Views studies) and a number, which is the statement's numerical order in the list.

All evidence statements that follow are based on videos and studies that are rich in direct user views.

Evidence statement measures

The evidence statements report two measures: amount and quality. The following conventions were used for amount of evidence:

- 1 to 2 studies - 'small amount'
- 3 to 4 studies - 'some evidence'
- 5 - 'moderate amount'
- 6 and above - 'good amount'.

In terms of quality, if more than 1 paper or video was used in an evidence statement, an average was taken of the weights assigned for each paper and video in order to provide an overall measure of quality for the evidence statement. For example, in a statement with 3 items, if the first were rated medium (+), the second high (++) and the third low (-), the evidence statement would be recorded as 'medium' level quality. If 2 papers were scored high (++) and 1 medium (+), the evidence statement would be recorded as 'high' level quality. If there were an even number of items of two quality levels (for example, two high and two medium), the evidence statement would be weighted on the lower side and recorded as 'medium' level quality.

TLAPV1	**Freedom and control provided by personal assistants** This evidence statement is based on a moderate amount of low quality evidence from 5 TLAP videos (TLAP 2009 −, 2010 −, 2010b −, 2012 −, 2012b −), all which explored the use of personal assistants from an employer's perspective. The videos state that employing a personal assistant gives service users the freedom and control to choose who, how and at what times help is received by them.
TLAPV2	**Reduced stigma by employing personal assistants** This evidence statement is based on 1 TLAP video of low quality (TLAP 2012a −), which described the experience of a service user with HIV using personal assistants. The video state that employing a personal assistant with the same values and aspirations helps reduce stigma.
TLAPV3	**Greater opportunity for activities through Personal assistants** This evidence statement is based on some low level quality evidence from 3 TLAP videos and one study of medium quality: the first video described

	a female service user being helped to go out bowling and to Age concern with the assistance of her PA (TLAP 2012b −), the second video described a female service user being helped to make trips and stay in hotels with the assistance of her PA (TLAP 2009 −), and third video described a male service user who was profoundly deaf being helped by his PA to go to football, clothes shopping and have a social life with friends (TLAP 2010b −). The study by Abbott et al. (2017+) about the use and experiences of using self-directed social care support by LGBTQI+ disabled men and women further consolidates this evidence statement. The study and videos found that Personal assistants help services users participate in activities that might otherwise be inaccessible to them.
V10	**Personal Assistants and positive impact on service user lives** This evidence statement is based on a good amount of medium level quality evidence from 3 studies and 5 videos. The studies and videos found that Personal Assistants make a significant positive difference to service users' lives. In the first study, Swain (2005 +), aimed to conduct a review of and support the development of service user involvement at all levels and within all areas of Leonard Cheshire activity. In the second study, Abbott et al. (2017+) investigated the use and experiences of using self-directed social care support by LGBTQI+ disabled men and women. Additionally, 5 TLAP videos (TLAP 2009 −, 2010a-, 2010b−, 2012a−, 2012b−) and one study (IFF 2008 +) examined the views of recipients of direct payments in their role as employers of PAs. These studies and videos collectively cite service users who rate PA's highly, citing more flexibility and control of choice and the added support of having PA's including, allowing them to have a job, social life and carry out activities which might otherwise be very difficult for them.
PA1	**Personal Assistants understanding and acceptance of sexuality and gender identity** This evidence statement is based on 1 study (Abbott et al. 2017, +), which examined the use and experiences of using self-directed social care support by LGBTQI+ disabled men and women. This study found that when people did not feel able to disclose their sexual orientation and gender identity to their PA, this had a negative impact on how they lived their day to day lives, including not receiving adequate support to express their sexuality. Receiving support to express sexuality led to a more positive experience. The study found that Personal Assistants' understanding and acceptance of the sexuality and gender identity of the person they are supporting has an important impact on that person's experience of support.

Expert witness testimony

The need for expert testimony

The Guideline Committee raised concerns that there was insufficient good quality research evidence on the experiences of people who used personal assistants.

Testimony

The full testimony from the expert witness can be found in appendix E. A brief summary of their testimony is given below.

Expert testimony was provided by a person with experience of employing personal assistants, and who had been part of the user-led development of this role. Key points made in his testimony included an emphasis on personalisation, choice and control and the valuable role that personal assistants can play in supporting this. Increased and more flexible use of personal budgets was linked to this, to enable people who use services to use their budget to employ their own staff.

The expert witness also talked about the support required to help people to recruit personal assistants, and to discharge their role as employers, including consideration of providing training and development opportunities for personal assistants. He also talked about the role that local authorities could play in helping to shape the market for personal assistants.

Included studies

Abbott D, Ottaway H, Gosling J et al. (2017) Lesbian, gay, bisexual and transgender, queer and intersex (LGBTQI+) disabled people and self-directed social care support. Bristol: University of Bristol

Norah Fry Research Centre (2010) 'It's all about respect': people with learning difficulties and personal assistants. Bristol: Norah Fry Research Centre

Social Care Institute for Excellence (2014) Dignity in Care – Privacy. SCIE TV Transcript. London: SCIE

Think Local Act Personal (2009) A service user's personal budget story. Video transcript. London: TLAP

Think Local Act Personal (2010a) A service user's personal budget story. Video transcript. London: TLAP

Think Local Act Personal (2010b) A service user's personal budget story. Video transcript. London: TLAP

Think Local Act Personal (2012a) Making it Real. Video transcript. London: TLAP

Think Local Act Personal (2012b) Making it Real – A woman with Alzheimer's. Video transcript. London: TLAP

3.7 What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?

Introduction to the review question

This question focused on what are effective approaches to gathering, synthesising and using the views of adults who use services in service development and improvement. It aimed to include studies which:

- seek to gather or monitor information about people's views and experiences or evaluate people's involvement in care planning and delivery
- have a comparison on control group, service evaluations or audits, except those which have not considered service user experience.

No cost effectiveness evidence, and very little effectiveness evidence was found for this review question, so an expert witness was also invited to provide testimony on this question.

Review question

4. What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?

Summary of the review protocol

This review question sought to identify evidence relating to evidence about what works in relation to how services collate information about the views and experiences of people who use adult social care services and how these activities impact on individual outcomes, including effectiveness and cost-effectiveness.

The review protocol originally sought to identify the following types of study design:

- Before and after or other controlled design, which measure and report on relevant individual outcome measures.
- Controlled trials or RCTs
- Studies of cost-effectiveness
- Evaluation studies where a control or comparison group is used
- Systematic reviews of effectiveness studies.

This was subsequently extended to include service evaluation and audit studies.

Population

Adults aged 18 or over who use social care services.

Intervention

Methods of gathering people's views and experiences of social care services.

Setting

All UK settings where care is delivered.

Outcomes

Relevant outcomes for review question 4 includes measures of impact on:

1. Wellbeing and quality of life (related to health, mental health and social wellbeing).
2. Engagement with services and care, including understanding relevant care and management issues where appropriate.
3. Choice and control.
4. Satisfaction of people who use services (including carer, family and advocate perceptions of how satisfied the people who use services are).
5. Perceived and objectively measured independence.
6. Ability to carry out activities of daily living with or without support.
7. Continuity of care.
8. Participation in social and community activities, including training and education, paid and unpaid employment.
9. Resource use.
10. Security and personal safety.

11. Costs.

See appendix A for full protocols.

How the literature was searched

Electronic databases in the research fields of social care, health, and social sciences were searched using a range of controlled indexing and free-text search terms combining the four concepts of:

- Views and experiences – including: views, experience, preference, perspective, satisfaction, dissatisfaction, feedback, learn, attitudes, expectation, complaint
- Setting (social care services) – including: social care, social provision, social service, community, residential, home, personal budget, direct payment, care plan
- Population (adults) – including: adults, older people, frail, elderly, homeless, disabled, disability
- Study type and outcomes – including: quality studies, evaluation studies, measures or outcomes, economic studies.

The search was restricted to human studies in the English language and published from 2000. A cut-off year of 2000 was chosen to include those studies that were most likely to be generalisable to the England and Wales policy and legislative context, and to manage the volume of evidence. Two significant policy and legislative changes at this time were the Health and Social Care Act 2001 and Valuing People 2001 that were intended to change the way people experienced health and social care services.

The search aimed to capture both journal articles and other publications of empirical research. Additional searches of websites of relevant organisations, and research archives or databases, were undertaken to capture literature that might not have been found from the database searches.

We additionally searched databases that contained a range of relevant video evidence of people’s experiences of social care. This included the Social Care Institute for Excellence (SCIE) Social Care TV and Think Local Act Personal (TLAP) video collection.

Economic evidence was searched for as part of the single search strategy, and included searching within the economic databases such as NHS Economic Evaluation Database (NHS EED) and the Health Economic Evaluations Database (HEED).

A call for evidence from stakeholders, providing an opportunity for any groups or organisations to submit relevant evidence, was also carried out at the beginning of the review.

Guideline committee members were also asked to alert the NICE Collaborating Centre for Social Care to any additional evidence, published, unpublished or in press, that met the inclusion criteria throughout the review.

The database and website searches were undertaken in March 2016. Update searching of the bibliographic databases searches took place in January 2017. When the update searches were ran an adjustment was made to the original search strategy to include the term ‘disabled’ in the population segment of the search.

See appendix A for full details of the search.

How studies were selected

Search outputs (title and abstract and only) were stored in EPPI Reviewer 4 – a software program developed for systematic review of large search outputs – and screened against the inclusion and exclusion criteria defined in the scope, which were as follows:

- Exclude on language. Not published in English.
- Exclude on date. Studies published prior to 2000 will be excluded. Systematic reviews where fewer than 80% or more of included papers meet our inclusion criteria – this includes publication date.
- Exclude on country. This study is not set in the UK.
- Exclude on population 1. Participants are less than 18 years of age.
- Exclude on population 2. Study is with carers (unless they are being used to give proxy views on behalf of people who use services).
- Exclude on intervention. Not a method for gathering views and experiences

- Exclude on setting. Not in one of the settings where adult social care is delivered as specified in the protocol.
- Exclude on outcomes. Not about service outcomes.
- Exclude on evidence type. Not comparative study.

Ninety-seven studies met the initial inclusion criteria and were included based on the title and abstract. After screening the full texts, this resulted in only a very small number of included studies. The inclusion criteria for study types and scope of the review question was extended to include studies that evaluated the acceptability, feasibility and internal validity of tools for gathering people's views and experiences that are intended to improve services (see intro to review question 4). This could include studies that did not have a comparison group if the study was evaluating the internal validity of survey tools, such as applying statistical tests of internal validity (for example, factor analysis).

Additionally, the inclusion criteria was extended to include some material from outside of the UK, as the effectiveness of methods and tools used for gathering people's views and experiences would not be as context specific as people's views and experiences of social care would likely to be.

Following full text screening, 10 studies were included.

See appendix B for full critical appraisal and findings tables.

Narrative summaries

Jones K, Netten A, Francis J et al. (2007) Using older home care user experiences in performance monitoring.

Methods: A cross sectional survey was developed as an extension to the national user experience survey (UES). All 150 councils with social services responsibilities were invited to participate in the extension study.

Data: Four questions were compulsory for the local authorities to include and two of these reflected the performance indicators:

Q1. Satisfaction. Overall how satisfied are you with the help from Social Services that you receive in your own home? (Best Value Performance Indicator (BVPI))

Q2. Social Services contact. Does anyone contact you from Social Services to check you are satisfied with the home care that you receive?

Q3. Suitable times. Do care workers come at times that suit you?

Q4. Changes. If you ask for changes in the help you are given, are those changes made? (BVPI).

The extended survey included additional questions on experiences of home care services and on age, gender, ethnic origin, receipt of help from others and whether the respondent had help with the questionnaire.

Country: England.

Setting: Community, residential. People receiving home care services.

Scoping framework areas: Active participation in lived experience of care.

Population: Older people receiving home care services.

Rating: Medium (+) quality.

Sample size:

Thirty-four local authorities out of 150 councils with social services responsibilities (CSSR).

Approximately 87,000 service users returned the original survey and nearly a quarter (21,350) of service users completed the extended version of the survey.

The response rate for the 34 participating councils ranged from 36% to 83%.

Analysis: Factor analysis was performed to identify the underlying constructs of home care quality.

Findings

The aim of the study was to test the degree to which the performance indicators actually reflected quality of service. The aims of the survey were to investigate:

- Whether the items used as a basis for the performance indicators adequately reflected home care quality
- Whether the ‘Satisfaction’ Best Value performance indicator used the most appropriate cut-off point
- The underlying constructs of home care quality and potential for developing measures of quality from the items.

The study finds that the Satisfaction survey item used as the basis of a Best Value indicator was highly associated with other indicators of user’s experience. Overall, 37% of the variance in overall satisfaction was explained by the positive and negative carer quality factors. However, ‘Contact with Social Services’ and ‘Changes’ were excluded from the factor, suggesting these were not linked to the overall construct being measured.

The results from the factor analyses suggest that using the extreme values (extremely satisfied, very satisfied) for each survey item represented a better measure for each factor, supporting the rationale for using this response level in subsequent analyses.

The findings have illustrated that two performance indicators designed to evaluate home care standards are important dimensions underlying quality: ‘Satisfaction’ and ‘Suitable Times’, and suggested that these were appropriate questions on which to base indicators.

Considerations: Participating local authorities were advised to minimise response bias by ensuring that the most of the questionnaires were self-completed. Guidance was provided to local authorities that assistance should be offered to black and minority ethnic service users, such as questionnaire translation or help to complete the questionnaire if the service user had limited literacy skills in their own language, however, 43% of people needed help to complete the questionnaire.

The hours of home care reported were relatively low, suggesting people with the highest care needs were under-represented in this sample. As an approach to gathering in people’s views and experiences to improve services, the study suggests that careful testing of the underlying constructs and meanings of service satisfaction should be conducted to ensure performance indicators measures what they intend to measure.

Malley J, Towers A, Netten AP et al. (2012) An assessment of the construct validity of the ASCOT measure of social care-related quality of life with older people.

Review Question: 4

Methods: A survey of older people receiving publicly funded home care services was conducted by face-to-face interview in several sites across England.

Data: The interviews gathered socio-demographic information and details about service receipt and informal support.

Country: England.

Setting: Service user's own home.

Scoping framework areas: All.

Population group: Older people.

This overall high (++) quality paper aims to demonstrate the construct validity of the ASCOT attributes. Data were collected face-to-face through computer aided personal interviews in people's homes during 2009 in 10 geographically dispersed locations across England.

Sample size: In total, 566 contacts were attempted from a sample of 778, producing 301 (53%) complete interviews. 68.1% female, 98.3% white ethnicity, 45.5% aged 80 to 89 years.

Analysis: Variables were hypothesised to be related and unrelated to each of the attributes that were collected. Relationships between these variables and the attributes were analysed through chi-squared tests and analysis of variance, as appropriate, to test the construct validity of each attribute. In addition to the evidence presented in this paper, the authors report that they used other methods to test content and face validity of the measures, such as expert review with social care stakeholders 'to identify attributes and ensure ASCOT's sensitivity to outcomes of interest to policymakers and relevance to the evaluation of social care interventions' (authors, p11). The authors also conducted a literature review exploring service users' understanding of social care outcomes.

Findings

A number of key findings are reported in relation to the sample of older people included. However, the key findings of interest to RQ4 are those reporting on the validity of ASCOT as a measurement tool. With respect to this, the authors report that it is feasible to use ASCOT with older people. They found that 'all 301 participants responded to every item in the instrument' (Authors, p12). Having said that, a significant minority of responses were proxy, which the authors report was at a higher rate than for other QoL measures/tools. The authors say that they think suggests were the result of the respondent lacking the capacity to answer survey questions – but to answering survey questions in general rather than the ASCOT questions specifically. The authors summarise from their analysis of the distribution of the ways the items were scored that they 'seemed plausible' (Authors, p12). They argue that: 'although the distributions were skewed towards good outcomes, if services are doing their job properly this type of distribution is to be expected' (Authors, p12). A key finding was that the items related to Food and drink and Accommodation were found to be highly skewed. The authors report that they tested the revised wording in a parallel piece of work (reference provided in the paper) and the new wording 'achieved better distributions in a sample of equipment users' (p12) – note this is a different group of sample respondents to the one reported in this paper. See limitations below – the authors report that more work needs done on testing the reliability of the ASCOT measures for older people and they also suggest the instrument should be validated on a sample of younger social care users.

Considerations: The authors report the following limitations with this study (p12): 'Firstly, the sample data only included older people receiving publicly funded home care services. As a result it is only possible to draw conclusions about the feasibility of using the measure and its validity for this client group in this setting. Secondly, the sample obtained here was not ethnically diverse, so we cannot demonstrate the validity of the measure amongst black and minority ethnic (BME) groups. It would therefore be of value to repeat this analysis with other client groups and, given the potential for some members of BME groups to have very specific preferences related to their cultural heritage, on a more ethnically diverse sample. Future work should also consider the reliability of the items.'

Murphy J, Gray CM, Cox S (2007) The use of Talking Mats to improve communication and quality of care for people with dementia.

Methods: Qualitative study in which people at different stages of dementia were interviewed about their wellbeing using unstructured (ordinary) conversation, structured conversation and Talking Mats conversation.

Data: The study deals with the experience of one group of people using adult social care services (that is, people with dementia), and considers one method of enabling them to communicate better (Talking Mats). It also considers whether the method enables everyone with dementia to communicate better, or only those in the early stages.

Country: England.

Setting: Care homes – but not made explicit.

Scoping framework areas: Respect, dignity and control, personalised support, information and communication.

Population: Older people.

'The central aim of this project was to examine the effectiveness of Talking Mats as a communication resource to enable people with dementia to express their views about their wellbeing. There were two principal research questions:

Do Talking Mats help people with dementia communicate?

Are Talking Mats effective for all people with dementia, or do only those in the earlier stages of the illness benefit'? (Authors, p24).

Rating: Low (−) quality.

Sample size: 31 people with dementia participated in the study. All participants in the study had dementia, although the severity varied. Although the study seems to imply that all participants were care home residents, for example by saying that care staff knew all of them individually, and by saying that it followed on from another similar study where 7 people who had recently been admitted to a care home participated, it is not actually stated explicitly.

Analysis: There is no statement in the report about getting ethical clearance for the study. However, the report does provide the following description of how they dealt with the issue of consent by participants: 'The problem of obtaining informed consent for research from people with dementia was addressed by using a three-stage consent procedure. This involved providing accessible information using visual clues, plain English and verbal explanations, approaches to staff and family members as well as to the people with dementia themselves, and a policy of ongoing consent whereby checks were made at every visit to ensure that the participants were happy to continue' (Authors, p24).

Almost nothing is stated in the report about how the data was collected and evaluated. The Talking Mats method of communication was compared with two other discussion methods by video-taping them and then comparing them. While this appears an appropriate design, the methods for comparing the ways of communicating are not described in detail. No data from the study, for example, the different interview methods, are provided. Only the findings are presented. The data cannot be described as 'rich'. The methods used to analyse the different ways of communicating are not described, and so their reliability cannot be assessed.

Findings

The study states that Talking Mats were ‘more effective’ (Authors, p25) than both structured and unstructured conversation in allowing people with dementia to communicate their views about their wellbeing. However, it is unclear how this finding can be substantiated given the very poor reporting of data and analysis.

The study found that Talking Mats improved participant understanding, researcher understanding, participant engagement and the amount of time the participant remained on track. The study authors state that these improvements were particularly evident in those with moderate and late-stage dementia. The study authors also state that those with late-stage dementia were still able to make use of the visual scale. Again, it is unclear how these findings can be substantiated.

Considerations: The report does not provide any details of how these conclusions were reached, save to state that the video recordings of the conversations were studied by two researchers and a final year psychology student. No examples are provided of how or why one form of communication was considered to be better than another, making it hard to know how much weight to give to the findings. Furthermore, participant characteristics, including age, gender, ethnicity and level of need of participants, is not reported. However, it seems likely (although not stated explicitly) that the participants in the study were all care home residents, and so would have had more need of support than the general population. Additionally, all suffered from dementia, although to varying degrees, which would also be an indicator of a higher level of need for support.

Given the research question's own apparent assumption that the research method is going to be a success, there needs to be more detail about how this evaluation was carried out before its objectivity and its results can be accepted.

Finally, the study's aims are clearly stated. However, there is concern that the second part of the research question ('Are Talking Mats effective for all people with dementia, or do only those in the earlier stages of the illness benefit?') appears to anticipate that the answer to the first part, about whether the mats actually work, will be yes.

Patmore C, Qureshi H, Nicholas E (2000) Consulting older community care clients about their services.

Methods: Qualitative views data from older people captured through individual interviews, focus groups or telephone conference.

Data: Views of older users of ‘social services community care’ about how they would like to be consulted about their services.

Country: England.

Setting: Own home, day centres and community centres.

Scoping framework areas: Respect, dignity and control, Information and communication.

Population: Older people.

This study presents the results of research with 88 older users of ‘social services community care’, who were interviewed in groups, individually, or through a telephone conference about how they would like to be consulted about their services. Individuals conveyed a clear general preference for individual interviews at home, which proved clearly more suitable than focus groups for people aged over 80. Written questionnaires were consistently criticised while views varied about individual telephone interviews (Authors, webpage).

Rating: Medium (+) quality.

Sample size: 88 older users of Social Services community care.

Analysis: Qualitative interview data was recorded with key phrases or expressions included verbatim. Emerging themes were identified and coded. Codes and subsequent analysis were modified and agreed through the researchers’ participation network meetings attended by IMCA caseworkers and their managers, hosted by the Department of Health, where representatives from each organisation could discuss with civil servants, and the research team, challenges concerning raising awareness of the pilot IMCA services among practitioners in health and social care, different interpretations of the IMCA role as set out in the MCA, and complicated IMCA casework.

Findings

Older people expressed a clear overall preference for individual interviews at home, which proved more appropriate than focus groups for people aged over 80. Written questionnaires were firmly criticised, while views varied about individual telephone interviews.

Home Interviews

All participants favoured individual home interviews because a wider range of people with health, mobility or vision problems could benefit from them compared with other methods. Home interviews also allowed plenty of time and capacity for an older person to express their views and in their own words, which some participants felt might not be possible in group discussions and written questionnaires.

People wanted to be interviewed by someone at management level with power to implement change based on their responses. Home interviews would also ensure that managers were directly confronted with the harsh realities of people's problems and living circumstances. Another recurrent theme was that senior managers had a 'moral obligation to witness first-hand the results of the services for which they were responsible' (Authors, webpage). Preference for a service manager as interviewer was identified only among older people – not among their family carers, nor among Social Services clients aged under 65 in a parallel study (Bamford et al. 1998).

Participants identified several desirable conditions that would help the interviews, including: plenty of notice to allow interviewees to prepare themselves; receiving an outline of the questions beforehand; the offer of a woman interviewer for those women who desired this; and feedback on the outcome of interviews (Study participants, page not cited – webpage).

Some older people suggested the following questions should always be asked in an interview, though without probing.

- Are you managing?
- Have you got enough money?
- Have you got enough care or help in the home?
- Can you get out of your house?
- Can you make yourself a hot drink?
- Do you get a diet that suits you?
- Can you choose your own shopping?
- Can you get a bath when you want to?
- How satisfied are you with: your health? Your services? Your level of happiness?
- Is there any type of help you want but which you’re not getting?

Other forms of consultation

i. Group discussions

Group discussions received modest views in terms of a consultation method. The most positive comments about group consultations came from a focus group at a day unit for older people recovering from functional mental disorders though this has not been described in the paper. The authors make a point to note the nuances to these preferences. For example, Asian older people attending a community centre for day care felt group discussions would be helpful in eliciting their views of that care. But they felt individual interviews were more suitable for understanding their individual needs and the overall adequacy of their services.

ii. Postal questionnaires

These were generally criticised on the grounds that those with sight problems and lack of manual dexterity were disadvantaged. Furthermore, the closed question style of many questionnaires, their impersonality, the sheer number of questions and the ease with which answers could be ignored, were seen as drawbacks.

iii. Individual telephone interviews

There were mixed views on this medium. Some members of the telephone conference felt the phone allowed frankness. Common concerns, however, were around hearing difficulties and distance, in that a telephone conversation could not show practical problems at home. Some people seemed to have an intrinsic dislike of phones or to have manual difficulties in using them. Others did not like being phoned unprepared. Opposition to telephone interviews was too widespread for them to be the sole method in a consultation. But enough people favoured them to suggest that they might be usefully offered as an option alongside other approaches.

iv. Personal diaries of service experiences

A suggestion that diaries might be used and could be periodically borrowed for analysis by senior managers generated mixed views. Those who disliked the idea explained that many service users had problems with writing. Similarly, some older people preferred the idea of managers making eye-witness assessments of the service, for example, by visiting to watch home care staff in action. But more older people were against this or angry that their own home might be used to 'subject hard-working, well-liked home care staff to a distressing experience of scrutiny' (Authors, webpage).

Choice

Generally the view was that choice in methods of consultation was fundamental to allow for the needs of different participants. People from minority ethnic groups broadly reflected the views of other participating groups, but also emphasised the importance of interviewing in the language of the interviewee’s choice.

Considerations: The paper is based on author interpretation of the views of older people and as such there are no direct quotes. The study design and methodology is not made explicit, and this may be because those aspects are reported in the larger study by (Patmore 1998) on which this paper is based. Similarly, there is no discussion on data analysis, including how researcher(s) themed and code transcripts/data. It is not possible to gauge how and whether researchers might have influenced study design and analysis or how the findings relate to their perspective, role and interactions with study participants. However, the researchers go into some length describing the issues with recruiting participants and ensuring that marginalised groups of older people, such as the housebound, are enabled to participate in the research.

Pizzola L, Martos Z, Pfisterer K et al. (2013) Construct validation and test–retest reliability of a Mealtime Satisfaction Questionnaire for retirement home residents.

Methods: Study to ascertain internal reliability and construct validity of a tool for gathering views on satisfaction with mealtimes (Mealtime Satisfaction Questionnaire, Martos 2010 unpublished paper).

Data: Mealtime Satisfaction Questionnaire (MSQ) data from 147 people in residential care (retirement home).

Country: Canada.

Setting: Residential care (retirement home).

Scoping framework areas: Respect, dignity and control.

Population: Older people

Rating: Low (−) quality.

Sample size: At time 1, 147 fully completed questionnaires received (749 questionnaires distributed, 180 received (24% response rate) of which 147 contained answers to all items. At time 2, the 180 respondents were contacted to complete the survey again. Sixty-four surveys received (35% response rate).

Analysis: Statistical analysis to determine internal reliability and test-retest reliability. Comparison with scores on a reference tool measuring wellbeing in older people (Philadelphia Geriatric Center Morale Scale) to determine construct validity.

Findings

The study showed an association between mealtime satisfaction and quality of life at a particular time point. Based on this, the study authors further suggest that, to improve quality of life, satisfaction with meal times should be measured and improved upon. However, this conclusion is not strictly supported by the findings of the study. No steps were taken within the study to improve mealtime satisfaction. It is therefore unclear whether improvement in mealtime satisfaction would indeed lead to improved quality of life.

Construct validity was measured using comparison with the Philadelphia Geriatric Center Morale Scale (PGCMS) – a scale used as a measure of wellbeing and quality of life in older adults. There was a moderate correlation between MSQ scores and PGCMS ($r=0.356$, $p<0.01$). Six individual items were positively correlated with the PGCMS (being offered disliked foods, appeal, taste, dining with tablemates, atmosphere and overall satisfaction). The overall association of these 6 items with PGCMS was $r=0.444$ ($p<0.01$).

Internal reliability was good (Cronbach alpha =0.83). Test-retest reliability was also good with intraclass correlation =0.91 (95% CI 0.65 to 0.88)[15].

Considerations: This is a non-UK study, although service provision in residential homes for older people in Canada is likely to be similar to the UK. The study considers a tool for gathering views on a specific element of satisfaction with services (mealtime), within a particular setting. It is unclear whether the tool or approach would be generalisable to other settings such as home care. Due to the relatively low response rate at time 2 (36%) calculation of test-retest reliability was based on a relatively small sample size (n=64). The PGCMS is used as a comparator but the reliability and validity of this tool is not reported.

Redley M, Clare I, Luke L et al. (2010) Mental Capacity Act (England and Wales) 2005: The emergent Independent Mental Capacity Advocate (IMCA) service.

Methods: Two types of data: Quantitative data in form of a 22-item checklist describing type and nature of referrals to the pilot Independent Mental Capacity Advocate (IMCA). Qualitative data through semi-structured interviews with managers and practitioners about their experiences and perceptions of IMCA casework.

Data: Views of managers and practitioners in health and social care to establish whether an IMCA service could protect the interests of adults who lack capacity, and understand any practical difficulties that IMCAs might face after the introduction of the statutory service. Views based on data from the 249 accepted referrals, involving 231 clients.

Country: England.

Setting: Seven advocacy organisations representing older people, people with learning disabilities, and individuals with mental health problems.

Scoping framework areas: Information and communication; continuity of care and transitions.

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[15] Note, point estimate does not lie within reported 95% confidence interval. It is unclear why this is the case.

Population: Older people, people with learning disabilities, and individuals with mental health problems.

Rating: medium (+) quality.

Fifteen months before the introduction in April 2007 of the IMCA service, the Department of Health asked seven advocacy organisations to provide pilot IMCA services. These services were evaluated in order to establish whether an IMCA service could protect the interests of adults who lack capacity and are without family or friends, and are faced with a potentially life-changing decision. The purpose of these findings was to inform the development of statutory advocacy, introduced in English legislation for the first time under the Mental Capacity Act (2005).

Despite this study reporting provider views only, it has been included for review because it reports on a model, namely IMCAs, which is about directly representing service users where they lack mental capacity to be involved in the service use tool development.

Sample size: The exact numbers of professionals in the sample was not made explicit. However, their feedback is based on their interactions with 231 clients broken down as: people with learning disabilities (40%); people with dementia (33%); a heterogeneous group consisting of adults with acquired brain injury, mental health problems, or a combination of these and other conditions; and people whose capacity was compromised solely by a physical illness (3%).

Analysis: Qualitative interview data was recorded with key phrases or expressions included verbatim. Emerging themes were identified and coded. Codes and subsequent analysis were modified and agreed via the researchers' participation network meetings attended by IMCA caseworkers and their managers, hosted by the Department of Health, where representatives from each organisation could discuss with civil servants, and the research team, challenges concerning raising awareness of the pilot IMCA services among practitioners in health and social care, different interpretations of the IMCA role as set out in the MCA, and complicated IMCA casework.

Quantitative data: the items on the checklist were piloted with representatives from each of the seven organisations, and the persons responsible for administering it were given face-to-face guidance in its use. The final version of the checklist was completed monthly and submitted to the research team. No further detail provided on the way this material was analysed.

Findings

Data presented are from the 249 accepted referrals, involving 231 clients.

Decision-makers in healthcare were more likely than those in social care to have undertaken their own assessment of an adult's decision-making capacity. Where social care decision-makers sought professional advice, this was almost always a psychologist or psychiatrist.

Sixty-three per cent of the 231 clients had family or friends who could, in principle, have been consulted, but this was deemed by decision-makers not to be 'practical or appropriate' (Code of Practice, para. 10.77). Reasons included, 'conflicts of interest' (17%), suspicions that they had abused the person lacking capacity (11%), disagreements among different family members (3%) or disputes with the decision maker (3%) (Authors, p1820).

Men and women referred for a change of accommodation (CoA) prior to discharge from hospital were significantly older than those referred for other types of decisions. Most (60%) referrals for such decisions related to people with a diagnosis of dementia. Most (60%) referrals concerning a serious medical condition (SMT) were people with a diagnosis of a learning disability.

Seventy-four per cent of the 231 clients used English or another spoken language, and nearly 17% used another means of communication (sign language, pictures or non-standard vocalisations). Significantly, IMCAs reported that over half of the 109 clients whose referrals were completed at the end of the evaluation were able to communicate some indication of their wishes that could be passed on to a decision-maker (Authors, p1820). This enabled IMCAs to support these individuals directly in participating in decisions made on their behalf.

Qualitative findings

i. Dealing with referrals

IMCAs spent just over 9 hours on each referral. The mean duration of involvement was 68 days and this did not vary significantly according to the type of decision. IMCAs believed that their involvement should end only when a decision had been made and fully actioned. 'The Code of Practice requires decision-makers to keep IMCAs informed of developments (para. 10.14), and to make available in a report the information and issues that they believed to be important in respect of a particular decision (para. 10.20)' (Authors, p1821).

ii. Time limited nature of IMCA role

Few practical difficulties, for example, interviewing clients privately or examining their records, were reported. However, what challenged IMCAs and their managers the most was that the 'decision-specific' and time limited (8 hours per client) nature of their role, which contrasted with other models of advocacy, and which stress the significance of spending time to get to know a client before representing his or her wishes (Department of Health, 2005).

iii. Change of accommodation decisions

Decision-makers in both health and social care were positive about involving advocates in substitute decisions about CoA. Decision-makers in social care were impressed with the IMCAs' knowledge and saw it as an approach to improve their understanding of a client's needs, as an aid to communication between members of multi-agency teams, and as a reminder of the centrality of the client's interests when making a substitute decision. The seven health care decision-makers who had worked with IMCAs in CoA decisions for in-patients shared similar views.

iv. Serious medical treatment decisions

Regarding decisions about an SMT, where healthcare decision-makers had not worked with an IMCA, most were not confident in involving anyone without medical training. This contrasted markedly in other situations where the same respondents were enthusiastic about the involvement of an IMCA in CoA decisions arising in the context of patients being discharged from hospital, as decisions were not thought of as entirely medical. It was felt that IMCAs might be able to resolve many of the difficulties currently facing hospital discharge services, particularly poor communication between health and social care teams, and delays and problems securing funding for residential placements.

The evaluation highlighted key differences between the different decisions. Health and social care decision-makers were generally very supportive of the need for, and potential benefits of, the involvement of advocates in CoA decisions. But concerning SMT decisions, healthcare decision-makers felt that advocacy was unnecessary, as clinicians believed that they were already able to establish and represent the views of patients lacking decision-making capacity, and furthermore a lack of medical training rendered their input as inappropriate.

Considerations: Researchers do not explain how they might have influenced study design and analysis or how the findings relate to their perspective, role and interactions with study participants. In terms of the quantitative aspect (questionnaire), authors do not make explicit if participants returned questionnaires monthly without fail. The authors stress: 'It should be borne in mind that the data presented here are derived from a pilot service, whose organisations were selected for the pilot in part because they were already judged able to deliver an IMCA service. Hence, the quantitative data may not be an accurate representation of the true proportions of IMCA cases with respect to decision types and the demographics of the client groups. In contrast, the managers and IMCA case workers interviewed for the qualitative data probably represent some of the most able advocates because the organisations from which they came had been selected by the Department of Health to take part in the pilot' (Authors, p1823).

Teale EA and Young JB (2015) A Patient Reported Experience Measure (PREM) for use by older people in community services.

Methods: Return rates and patterns of missing data were examined. The scaling properties of the PREMs were examined with Mokken analysis.

Data: Intermediate Care Patient Reported Experience Measure (PREM) Intermediate care services from 31 bed-based and 143 home-based or reablement intermediate care services in England.

Country: England.

Setting: Intermediate care described as bed based (for example community hospitals) and home based.

Scoping framework areas: Care and support for people's needs.

Population: Older people.

Rating: Medium (+) quality.

Sample size (see table below):

Type of care	Number of services	Target number of participants	PREMS returned	Return rate
Bed-based	131	6550	1832	28%
Home based	95	23,750	2983	13%
Reablement	48	12,000	1644	14%
Overall	274	42,300	6459	15%

The study aims to describe the development of Patient Reported Experience Measure (PREM) suitable for use in Intermediate care services and to examine their feasibility, acceptability and scaling properties. The study aims to examine the extent to which the PREM items may be converted to a single numerical score. These additional survey questions were developed by a group of 29 patient and practitioners IC expert consensus group and incorporated into the 2013 The National Audit of Intermediate Care (NAIC) survey.

Analysis: Tests for reliability were used using the Mokkan Scale to determine the Loevinger coefficient. The Loevinger Hi is a measure of uni-dimensionality: that is whether or not an item is measuring the underlying trait. (0.3–0.4 indicates a weak scale, 0.4–0.5 is moderate and >0.5, a strong scale.) Survey returns from the Reablement and home-based IC services were combined for the Mokkan analysis.

Findings

There appeared to be a difference in the rates of returns depending on whether the questionnaire was delivered by hand or by post – people in bed-based services were more likely to be given the questionnaire to complete by hand, and people in home-based services were given the questionnaire by post, with greater return rates from people in the bed-based services. The rates of return were relatively low by any measure, but as these new questions were part of a much larger service users audit questionnaire, it may not be a reflection on the feasibility of the new intermediate care scale.

The overall measures of uni-dimensionality of each item, either bed based or home based was low to moderate. The authors conclude that the items scores can be summed to provide an overall score of IC service user satisfaction.

However, one question: ‘Staff that cared for me in this service had been given all the necessary information about my condition or illness by the person who referred me’ was poorly completed in both bed-based and home-based returns, probably indicating that a person can’t know whether staff have all the information they need or not.

Considerations: There was no baseline demographic information on patients who participated, as a result it was not possible to identify any underlying patterns of people who did not complete the questionnaire, or if the people who did complete the questionnaire were representative of people who use intermediate care services.

Questions asked in surveys have to be knowable to the person who completed the survey. A single survey user experience score can make this scale comparable to others and compared to other services. Reliable questions on the service user experience can be used to feedback people’s experiences and views on the quality of the care they receive to improve IC services in the future.

Towers AM, Smith N, Palmer S et al. (2016) The acceptability and feasibility of using the Adult Social Care Outcomes Toolkit (ASCOT) to inform practice in care homes.

Review Question: 4

Methods: Survey analysis of the current SCRQoL, as measured by ASCOT. Focus group discussions (with staff initially and then residents and their families) to provide feedback on changes in practice.

Data: Quantitative data for domains of the SCRQoL (ASCOT) and views from staff about the feedback provided by the researchers.

Country: England.

Setting: Residential care.

Scoping framework areas: All.

Population group: Lacking capacity, older people.

This medium (+) quality paper aims to evaluate the impact of quality of life (QoL) over time using the SCRQoL aspects of the ASCOT toolkit on care home residents with dementia. The specific objectives were to: 1. Design a feedback-intervention based on the evidence collected using the CH3 toolkit (observational notes and interviews) and pilot it in a small sample of care homes in England. 2. Examine the acceptability of this feedback to care home staff and explore whether there were any reported changes in staff practice or measurable changes in residents' SCRQoL after the feedback had been delivered. 3. Examine and report new inter-rater reliability analysis on the CH3 approach.

Sample size: Two nursing homes owned by a national care home provider and two residential homes run by a small independent provider took part (all homes accepted people living with dementia and varied in size between 29 and 64 beds). The two residential care homes only accepted women residents (85 % of the total sample were women). All staff were invited and encouraged to take part in the research. All permanent residents were invited to take part in the research, including people with dementia, other cognitive impairments and communication difficulties. The only exclusion criteria were those who were there for respite and short-term care and those currently in hospital. Table 4 is the only place sample size is stated – 20 residents. Response rates ranged from 23% in one of the nursing homes to 54% in one of the residential care homes. Attrition rate was 16% (one care home was removed from the study at time two). Residents ranged in age from 73 to 97 years old, with a mean age of 86 years.

Analysis: The main outcome measure is current SCRQoL, as measured by ASCOT. Data were analysed using a variety of quantitative techniques as appropriate: Mann-Whitney U-test, General Linear Model was used instead. Chi-squared (X2) tests of association and correlations, and Wilcoxon signed-rank test for comparisons between time one and time two. It is not reported how the feedback group discussions were analysed but this data is presented thematically in the paper.

Findings

While the health and social care needs of the residents in the research declined over the time period being observed in the research, their QoL measures remained the same. The authors conclude from this that: ‘homes maintained residents’ quality of life but did not improve it’ (Authors, p12).

No differences in the SCRQoL between the residential care home with nursing needs and the one without were found after controlling for the differences in residents’ needs and characteristics related to setting.

Staff and managers offered a generally positive view of the data collection process and feedback intervention. The authors comment that ‘Staff and managers agreed with the feedback they were given and felt it accurately reflected the areas of quality of life they do well at (personal cleanliness and comfort, accommodation cleanliness and comfort, safety and dignity) but also identified areas they struggle to make time for (choice over food, control over daily life, social participation and occupation)’ (Authors, p9–10).

The authors report that the feedback provided by them led to changes in practice. For example, one care home manager comments: ‘I completely changed the whole setup of the working day. So I looked at smaller groups of residents, because the staff were coming back to me and saying, “We haven’t got time to complete all of our tasks with so many residents.”.... They now have more time to spend with the residents in terms of social care; the little things, painting nails, and so on and so forth, and the lipstick and it's all very, very important. So that took the onus off of a task-orientated workload' (Care Home Manager Nursing National Chain, p10).

Considerations: Results are based on a very small sample (20 residents), which the authors comment was due to the difficulties recruiting and retaining homes to the research. No views data are from the residents. Much of the data collected by the SCRQoL was completed by staff as most of residents lacked capacity to take part directly (Page 6, a mean of 53% of dementia residents who participated in this research lacked capacity). Page 12, the authors comment: 'During this study, researchers often rescheduled interviews and observations with individual residents because of poor health and noted that residents have "good and bad days". If observing on a bad day, ratings might indicate a lower than average outcome for that individual. If observing on a good day, the opposite might be true. Methodologically, this is a limitation of measures relying on 'snapshots' of information about residents' lives.' The authors also reflect on their own role in the research process and what impact that may have had on ongoing changes in practice. They say that 'had staff collected the data and made their own ratings of residents' lives, using ASCOT, it may have had more impact on care practice than a feedback intervention and would also have had sustainability beyond the life of the study, providing potential for ongoing benefits for residents and staff'.

Turnpenny A, Caiels J, Whelton B et al. (2016) Developing an easy read version of the adult social care outcomes toolkit ASCOT).

Review Question: 4

Methods: The study combined survey development and pre-testing methods with approaches to create accessible information for people with intellectual disabilities. A working group assisted researchers in identifying appropriate question formats, pictures and wording.

Data: Focus groups and cognitive interviews were conducted to test various iterations of the instrument. Respondents were people with an intellectual disability and/or autism.

Country: South-east of England.

Setting: Own home.

Scoping framework areas: All.

Population group: Older people, people with learning disabilities.

This medium (+) quality paper aims to contribute to these by adapting and improving an existing measure for use by people with intellectual disabilities and autism. The respondents gave feedback on the first revision of the ASCOT-ER.

Sample size: Eight focus groups with a total of 32 participants with an intellectual disability and/or autism were conducted. Twenty-two one-to-one cognitive interviews were conducted with people with an intellectual disability and/or autism in testing the second revision of the instrument.

All participants, including the working group, were recruited through self-advocacy organisations and service providers for people with intellectual disabilities in the South East of England. They all had capacity to consent, could express themselves verbally and were able to contribute to discussions in English.

Analysis: Each focus group tested two or three domains – using the approach described in the methods section of the paper – and each domain was tested at least twice in different focus groups. The analysis had these key questions to address:

1. Can participants understand the questions and response options? Are they interpreted in accordance with the domain descriptions and answered in a way that is relevant to the context? Are questions and responses options interpreted consistently across respondents?

2. Are respondents able to answer the questions, in particular: a. are their answers based on their experiences? b. Is there any evidence of systematic bias in responding?

3. Do the pictures help respondents to answer the questions, particularly: a. how well do the pictures reflect the content of the questions? b. Does the visual response scale help respondents to choose an answer? Is the difference between the response options clear?

Findings

Findings are reported in relation to understanding and interpreting the questions within the ASCOT-ER:

The authors report the question item for the Food and Drink section was understood by focus group participants and cognitive interview respondents (page 6). They say that: ‘Responses reflected different experiences, and attention was paid to the variety and balance of the food and drink that people were consuming, as intended by the domain description’ (Authors, p6).

For the domain Personal cleanliness and comfort (Being presentable), the authors reported the items were less well understood. For example, the word ‘presentable’ was highlighted as being potentially difficult, and nearly all respondents commented that they had never heard it.

For the domain Accommodation cleanliness and comfort, the authors say that the question was understood without any difficulty by focus group and cognitive interview participants. Respondents living in different contexts (for example, some were in shared accommodation) were able to reflect well on those contexts to respond to the question.

The domain Personal safety raised important issues. The authors report that discussions with the working group revealed that this was cognitively too challenging because most respondents reported feeling very different at home and in the community. For example, one participant explained that he felt safe in his home but was more anxious when outside because of being the victim of a previous assault. These considerations led the research team to split the original question into two questions: one relating to safety inside the home, and the other to how safe people feel when they are outside in their neighbourhood and local community. The authors report that all respondents understood consistently the two new questions.

For the domain Social participation and involvement, the authors report focus group participants describing the question as easy to understand, and say all participants were familiar and happy with the term ‘social life’. They also report that the cognitive interview participants ‘appeared to understand the question and responded adequately reflecting on their experiences of seeing and keeping in touch with people important to them' (Authors, p7).

For the domain Occupation, which asks respondents to consider all activities in their daily lives using a series of bullet points, the question was considered very long and consequently the authors reported that 'some respondents needed to read (hear) it more than once to process it fully'. Nevertheless, they argue that 'participants did not need any further explanation nor did they highlight any difficult words' (Authors, p8).

The authors report that the domain Control over daily life alongside Dignity presented particular challenges during the development of ASCOT-ER. For example, the authors say that during the focus groups a number of participants – particularly those with Autism – held the view that the question was not specific enough and therefore difficult to answer. They go on to say that other participants with intellectual disabilities found the term 'control' confusing. In response to comments from respondents the wording was changed to be about choice rather than control. The authors report that all but one respondent appeared to understand the revised wording.

For the domain Dignity, the authors report that an early version tested in focus groups included the term 'respect' ('dignity means being treated nicely and with respect') and this term was highlighted by participants as problematic. The revisions to the tool led to the word 'respect' being removed and dignity being reworded as 'being treated nicely and kindly'. Concerns were also raised by respondents about the concept of 'paid staff'. The authors say: 'A further concern was that people with intellectual disabilities who use social services often come into contact with more than one paid staff member, who might have a different attitude or approach towards supporting people. Therefore, answering this question potentially requires a high level of generalisation that might be difficult for some respondents; cognitive testing paid particular attention to exploring this'.

Finally, a key consideration for the authors was how well people with intellectual disabilities would respond to tools with sets of response categories and if they could reliably assign themselves to an answer. The authors found that when it came to specific response options, longer descriptors were more useful than those consisting of one or two words, like those commonly used in Likert-type scales. The use of happy and sad faces were reported as being helpful because people were already familiar with these images but some participants commented that they were 'childish' and a lack of neutral response and face – the ASCOT measure uses a four-point scale – was reported as problematic.

The authors report substantial changes being made to the original ASCOT-ER questionnaire. They argue that involving people with intellectual disabilities and autism in the questionnaire revisions helped by 'identifying and including images that are both acceptable and relevant to the majority of participants' (Authors, p10). The authors conclude (p11) that the findings suggest that while most people with intellectual disabilities and autism should be able to use and engage with the ASCOT-ER, the ASCOT-ER would benefit from further systematic testing, particularly around validity and reliability.

Considerations: Page 10: the authors note a few limitations: First that use of cognitive interviews can influence the data produced (they cite DeMaio & Landreth 2004; Presser et al. 2004). The authors say that 'interviewers' contributions can shape interviews by providing confirmation, functional remarks, expansive probes and feedback, as well as re-orientate and keep respondents motivated' and they acknowledge that the 'presence of the interviewers may have helped respondents with intellectual disability in a way that would not be reflective of a self-completion survey'. Another limitation they discuss relates to the development of ASCOT-ER as part of the Adult Social Care Survey (ASCS). They say that: 'participants were not necessarily representative of the population of social care users who would receive the survey'. However, they argue that because the main aim was to cognitively test the questionnaire for people with intellectual disabilities and autism, the study participants were potentially more able than the general service user population.

Willis R, Evandrou M, Pathak P et al. (2016a) Problems with measuring satisfaction with social care

Review Question: RQ4

Methods: In-depth individual interviews with adult service users and informal carers from white British and South Asian ethnic groups in three Local Authority regions.

Data: Questions were mostly open-ended and focused on experiences of using social services. In addition, there was one closed-ended question to ask about satisfaction ratings. Interviews were conducted in English, Hindi or Gujarati, depending on the first choice of the participant.

Country: England.

Setting: Services used included domiciliary care, residential care, day centres and carers' groups.

Scoping framework areas: Care and support for people's needs.

Population group: Black and minority ethnic and all service users.

The focus of this paper rated medium (+) quality was the measurement of satisfaction with social care services. Examples from a qualitative exploration of satisfaction with adult social care services among people of different ethnic groups are discussed. These data are used to support the argument that existing quantitative measures of satisfaction with social care do not accurately capture the views of respondents. Comparison is made between a black and minority ethnic group of service users and a white British group. This paper focuses on how participants spoke about the concept of satisfaction itself, and their struggles to reconcile their numerous experiences with a single rating.

Sample size: Eighty-two participants comprised of 46 people who use adult social care services, as well as 36 carers. Eighteen to ninety, with the majority aged over 65; 39 South Asian and 43 white British. The researchers used purposive and snowballing sampling methods to recruit participants from the two ethnic groups in the study. 'Service users and carers were recruited through several means. First, invitation letters were posted by Local Authority Social Services departments to service users and carers. Second, gatekeepers of interest groups were approached for advice on how to recruit participants. Permission was given for the research team to visit temples, mosques, churches, carer groups, social groups, etc. in order to introduce the project to potential participants. Finally, people who had taken part in the study were asked if they would mind passing on the researchers' details to their friends and family members' (p591).

Analysis: ‘Data were analysed using thematic analysis (Braun & Clarke 2006) and the principles of open coding, constant comparison, negative case analysis and memo writing (Mason 2002). In addition, some a priori codes derived from the literature review were used. Data were not forced into these a priori codes; instead, they were used as reminders to look for instances of theoretical importance in the data. The NVivo 10 software program was used to facilitate data storage, categorisation and retrieval. Two coders independently coded the transcripts, and compared their coding. Codes and themes were developed through discussion with the project team, and checked by returning to the transcripts’ (Authors, p591).

Findings

The study has two main concerns. One is to examine, given the lower satisfaction ratings given to adult social care services by black and minority ethnic communities, whether South East Asian service users in the studies area were satisfied and dissatisfied with the same aspects of care services as the white British sample. The other concern of the study was to inquire in greater depth, using qualitative methods, what service users’ satisfaction rating meant.

Satisfaction ratings

Few participants were completely satisfied with their experience of social services, yet the research found a bias towards positive satisfaction ratings as reported in prior research (Collins & O’Cathain 2003). The global (single) question of satisfaction required participants to reduce their whole, varied experience to a single user satisfaction rating. For some individuals, this was problematic, for example, if some elements of experience had been good and some bad it was hard to decide on a rating.

Some asked the interviewer how they should resolve this problem to answer the question ‘correctly’:

‘My main thing is that what they said that they were going to do, they didn’t do, and it’s been over a year. I am not satisfied with that but with everything else I would say that I am very satisfied. So which one should I tick?’ (laughs) (Service user 14, SA, p592).

The authors note that it is interesting to explore how the participants justified their positive satisfaction rating despite their poor experiences. Some participants did this by omitting the dissatisfactory aspect of care, for example:

‘But, otherwise [not enough staff at the day centre], they were excellent, I wouldn’t, wouldn’t decry them at all. It was just silly little things, you know, but they’re only minor irritations, they’re not major problems so we don’t worry about them’ (Service User 04, White British, p592).

Some participants were willing to overlook even potentially serious matters when making their satisfaction judgement:

‘I would say that apart from that one incident [medication mistake while in respite care], I was totally satisfied there, very satisfied, yes’ (Service User 39, White British, p592).

Some participants mentioned mitigating factors to justify the positive satisfaction rating, despite experiencing problems.

‘She [my social worker] was fantastic, so I was extremely satisfied with her, and I felt that she heard me, and I felt that she got through the whole process as quickly and as effortlessly as possible given the situation’ (Service User 31 South Asian, p592).

Another difficulty with the satisfaction question is that it does not allow for change over time:

‘So that’s when it kind of went from very satisfied – well it went from extremely satisfied when she had two guys that she knew very well who were there for most of the time ... but then like I said, there was a change in provider by the council ... and when that happened it started to become a little bit fragmented and disjointed in terms of consistency of who came to see them and the times which they came to see them. So she kind of slipped towards the other end of the scale [of satisfaction]. So I can’t really give you like one definitive [answer]. It’s more temporal’ (Carer 33, WB, p592).

The meaning of ‘quite satisfied’

The meaning of the Likert scale categories was questioned in some of the interviews. There were different understandings of what ‘quite satisfied’ means. For example, one participant gave a rating of quite satisfied despite the negative treatment provided to her husband, the care recipient. Another participant defines ‘quite satisfied’ as ‘alright’ but ‘nothing brilliant’. In other words, the care was adequate.

Satisfaction comparison between ethnic groups

The study found that both the white British sample expressed dissatisfaction with the same aspects of the adult social care service. However, South East Asian participants also wanted linguistic assistance, either by survey questionnaires being translated, or by a translator helping them to fill the questionnaires in. The researchers also noted that 'the two people who mentioned fear of retribution for making a negative evaluation were South Asian' although this did not necessarily 'suggest that South Asian service users are more likely to feel this way; the sampling approach adopted for this study makes such generalisations unwise' (p594).

Considerations: Despite the rich user quotes, the report does not provide information about questions asked or information about the context or setting in which the interviews, which provide the data for the study, were carried out. Furthermore, very little rich data is provided to illustrate the other matter under consideration, whether there are differences in satisfaction between South East Asian and white British service user satisfaction ratings.

Evidence statements

The evidence statements were guided using the 6 ‘scoping framework’ (refer to the review background document for GC5) higher order categories:

- Respect, dignity and control
- Personalised support
- Information and communication
- Active participation in lived experience of care
- Continuity of care and transitions (including access to care)
- Care and support for people’s needs.

These themes are represented within the evidence statements that follow. The statements do not speak to individual themes; the statements often reflect several of the themes.

ALL evidence statements that follow are based on studies that are rich in direct user views.

Evidence statement measures

The evidence statements report two measures: amount and quality. The following conventions were used for amount of evidence:

- 1 to 2 studies - 'small amount'
- 3 to 4 studies - 'some evidence'
- 5 - 'moderate amount'
- 6 and above - 'good amount'.

In terms of quality, if more than 1 paper was used in an evidence statement, an average was taken of the weights assigned for each paper in order to provide an overall measure of quality for the evidence statement. For example, in a statement with 3 papers, if the first were rated medium (+), the second high (++) and the third low (-), the evidence statement would be recorded as ‘medium’ level quality. If two papers were scored high (++) and one medium (+), the evidence statement would be recorded as ‘high’ level quality. If there were an even number of studies of two quality levels (for example, two high and two medium), the evidence statement would be weighted on the lower side and recorded as ‘medium’ level quality.

Evidence statements from review of literature on what methods and approaches are effective and cost-effective for gathering, monitoring and evaluating the experiences of people using adult social care services

RQ4.1	**Adapting data collection to people's needs** This evidence statement is based on some evidence of overall medium level quality. The studies found that methods used to collect peoples’ views and experiences to improve services are more effective when adapted to the person’s preferences and their ability to participate. The first of these studies (Jones et al. 2007 −) looked at the degree to which best value performance

	indicators represented people's satisfaction with home care. Local authorities were advised to provide help to complete the survey, particularly for black and minority ethnic groups (such as with translations or help with completion). The study also indicated that people with higher support needs were under-represented in the sample. The second study (Redley et al. 2010 +) looked at a pilot of the Independent Mental Capacity Advocate (IMCA) role and found, of the people referred for the service, a quarter of participants did not speak English or another spoken language and nearly 17% used other means of communication (sign language, pictures or non-standard vocalisations). The third study (Patmore et al. 2000 +) was a qualitative study that looked at how best to consult older community care clients about their services and found written questionnaires were particularly difficult for people with sight problems and lack of manual dexterity. The number of questions in a questionnaire was also found to be a barrier to completion. The fourth study (Teale and Young 2015 +) tested the scalability of the Patient Reported Experience Measure (PREM) for people who used intermediate care services and found that there was a greater return of completed surveys when people were given the questionnaire to complete in person (bed-based intermediate care group) instead of by post (home-based intermediate care group).
RQ4.2	**User involvement in tool development** This evidence statement is based on some amount of evidence of overall medium level quality that the tools used to translate service user views and experiences into quality indicators and service monitoring are effective when developed by stakeholders and tested to measure what they intend to measure. The studies also found that tools used to translate service user views and experiences into quality indicators and service monitoring are effective when developed by stakeholders and tested for validity, feasibility and acceptability. In the first of 3 studies (Jones et al. 2007 +) found that the Best Value Performance Indicators of 'satisfaction' and 'suitable times' were closely related to other indicators of service user experiences. Other items were not associated with the construct of service user satisfaction (such as 'contact with social services'). The second study (Patmore et al. 2000 +) found that, as part of the requirements of the Best Value reviews, there needs to be effective methods for consulting frail older people. Frail older people consulted about their preferred methods of giving their views and experiences said there was a preference for home-based interviews, but also a preference for a senior member of the management staff to conduct them – people wanted to be interviewed by someone who had power to implement changes. The third study (Teale and Young 2015 +) found that involving a group of patient's representatives, practitioners and other professionals in a Delphi consensus process was an effective way to inform new questions that were relevant to people who used intermediate care services.
RQ4.3	**Mealtime satisfaction of older adults in residential care** This evidence statement is based on 1 study (Pizzola et al. 2013 −) of low quality that mealtime satisfaction of older adults in residential care correlated with overall quality of life and wellbeing for older people in residential care. This study found that the Mealtime Satisfaction Questionnaire (MSQ, Martos 2010, unpublished paper) had good internal reliability (Cronbach alpha =0.83) and test-retest reliability (ICC=0.91, 95% CI 0.65 to 0.88). Scores on the MSQ showed a moderate correlation with a measure of quality of life. The study found

	that mealtime satisfaction of older adults in residential care is correlated with overall quality of life and wellbeing for older people in residential care.
RQ4.4	**Patient Reported Experience Measure (PREM)** This evidence statement is based on 1 study (Teale et al. 2015+), of medium quality, which investigated the properties of (PREM) for Intermediate Care. The items on the PREM were found to be correlated with overall satisfaction with intermediate care. The study found that Patient Reported Experience Measure (PREM) can be used to measure user satisfaction with intermediate care.
RQ4.5	**Talking Mats** The evidence found relating to the effectiveness of Talking Mats (Murphy et al. 2007−) is of insufficient quality to derive an evidence statement.
RQ4.6	**Supporting decision making for people who lack capacity** This evidence statement is based on a small amount of evidence from one mixed-methods study of medium level quality that people who lack capacity can be supported in participating in decisions. Redley et al. (2010 +) evaluated a pilot Independent Mental Capacity Advocate (IMCA) service and found that, in over half of their cases, people who lacked capacity were supported in participating in decisions made on their behalf. The study found that people who lack capacity can be supported in participating in decisions.
RQ4.7	**Advocacy interviews** This evidence statement is based on a small amount of evidence of medium quality from one mixed-methods study that time limits to advocacy interviews is a barrier to delivering person-centred care. Redley et al (2010 +) evaluated a pilot Independent Mental Capacity Advocate (IMCA) service and found the time-limited nature of the interviews allowed to a person who lacked capacity was a barrier to getting to know them and to delivering a truly person-centred approach in helping their clients express their wishes. This study found that time limits to advocacy interviews is a barrier to delivering person-centred care.
U1Q4	**Using ASCOT and SCRQoL** This evidence statement is based on some studies of overall medium quality, which evaluated the validity of using ASCOT and SCRQoL on various groups of adult social care service users. In the first of 3 studies, Malley (2012 ++) indicated that older people, especially those lacking capacity, may have difficulties understanding some of the questions. It also recommended that the instrument should be validated on a sample of younger social care users as it had only really been tested on older people. The second study (Turnpenny 2016 +) reported that several participants with learning difficulties and autism had difficulties with interpreting questions in some of the tool domains. The Willis R et al (2016a +) study suggested differences in satisfaction levels between black minority ethnic and white-British service users, but the understanding of the results is hampered by the variations in responses to Likert scales and concerns over positively biased responses. The studies found that tools measuring levels of satisfaction such as the ASCOT and SCRQoL among service users are promising tools, but require some modifications and further testing.
U2Q4.	**Satisfaction tools** This evidence statement is based on on 1 study of medium quality (Towers 2016 +), which evaluated the impact of quality of life over time using the SCRQoL aspects of the ASCOT toolkit on care home residents with dementia. As well as evaluating the toolkit, the study provided feedback to staff about the results and asked them to reflect on this. The study authors reported some

	evidence of changes in practice because of this feedback. The study found that feeding back results of satisfaction tools to social care management can lead to positive improvements in practice.

Expert witness testimony

The need for expert testimony

We were unable to find any evidence in relation to cost-effectiveness of different methods for gathering, monitoring and evaluating the experiences of people using adult social care services, and little effectiveness evidence.

Testimony

The full testimony from the expert witness can be found in appendix E. A brief summary of their testimony is given below.

Expert testimony was provided by an academic working to develop methods for gathering the experiences of people who use adult social care services. Her testimony confirmed that there is little economic evidence regarding effective methods for gathering the views and experiences of people using services.

Her testimony highlighted that a single approach to surveying people using services was unlikely to be effective, and that a range of methods would be required in order to tailor response formats to people’s needs, and address a range of barriers to participation (including communication problems, sensory impairments and physical disabilities). She highlighted the importance of ensuring that surveys do not systematically exclude particular user groups, and of analysing ‘non-response’ as a way of improving this in the future. She also emphasised the importance of involving people who use services in survey design and data collection.

Included studies

Jones K, Netten A, Francis J et al. (2007) Using older home care user experiences in performance monitoring. Health and Social Care in the Community, 15: 322–32

Murphy J, Gray C M, Cox S (2007) The use of Talking Mats to improve communication and quality of care for people with dementia. Housing, and Care & Support, 10: 21–27 p7

Malley Juliette N, Towers Ann-Marie, Netten Ann P, Brazier John E, Forder Julien E, Flynn Terry (2012) An assessment of the construct validity of the ASCOT measure of social care-related quality of life with older people. Health and quality of life outcomes, 10: 21

Patmore C, Qureshi H, Nicholas E (2000) Consulting older community care clients about their services. Research, and Policy and Planning, 18(1)

Pizzola L, Martos Z, Pfisterer K, de Groot , Lisette, Keller H (2013) Construct validation and test–retest reliability of a Mealtime Satisfaction Questionnaire for retirement home residents. Journal of Nutrition in Gerontology and Geriatrics, 32(4): 343–59

Redley M, Clare Isabel C. H, Luke L, Holland Anthony J (2010) Mental Capacity Act (England and Wales) 2005: The emergent Independent Mental Capacity Advocate (IMCA) service. British Journal of Social Work, 40: 1812–1828

Teale E A and Young J B (2015) A Patient Reported Experience Measure (PREM) for use by older people in community services. Age and Ageing, 44: 667–72

Towers A M, Smith N, Palmer S, Welch E, Netten A (2016) The acceptability and feasibility of using the Adult Social Care Outcomes Toolkit (ASCOT) to inform practice in care homes. BMC Health Serv Res, 16: 523.

Turnpenny A, Caiels J, Whelton B, Richardson L, Beadle-Brown J, Crowther T, Forder J, Apps J, Rand S (2016) Developing an easy read version of the adult social care outcomes toolkit (ascot). Journal of Applied Research in Intellectual Disabilities, Advance online publication. doi: 10.1111/jar.12294

Willis R, Evandrou M, Pathak P, Khambhaita P (2016a) Problems with measuring satisfaction with social care. Health & Social Care in the Community, 24: 587–95

3.8 Evidence to recommendations

This section of the guideline details the links between the guideline recommendations, the evidence reviews, expert witness testimony and the Guideline Committee discussions. Section 3.8.1 provides a summary of the evidence sources for each recommendation. Section 3.8.2 provides substantive detail on the evidence for each recommendation, presented in a series of linking evidence to recommendations (LETR) tables.

3.8.1 Summary map of recommendations to sources of evidence

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
1.1 Overarching principles	
1.1.1 Recognise that each person who uses services is an individual. Use each person's self-defined strengths, preferences, aspirations and needs as the basis on which to provide care and support to live an independent life[16].	GC consensus, NICE Guideline on patient experience in adult NHS services recommendation 1.1.1).
1.1.2 Support people to maintain their independence. This means finding out what people want from their life, and providing the support and assistance they need to do this[17].	NICE Guideline on patient experience in adult NHS services, recommendation (1.2.10), LD2, LD3
Co-production and enabling people to make decisions	
1.1.3 Respect people's right to make their own decisions, and do not make assumptions about people's capacity to be in control of their own care and support (for example, if the person is severely disabled).	BF1, TLAPV3, GC consensus
1.1.4 Actively involve the person in all decisions that affect them.	BF1, TLAPV3, GC consensus
1.1.5 Provide support to people, if they need it, to express their views, preferences and aspirations in relation to their care and support. Identify and record how the person wishes to communicate and if they have any communication needs (in line with the Accessible Information Standard). This could include: • advocacy support • an independent interpreter (that is, someone who does not have a relationship with the person or the services they are using) to enable people to communicate in a language	LD1, LD4, RQ4.7, V1

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[16] This recommendation is adapted from the NICE guideline on patient experience in adult NHS services.

[17] This recommendation is adapted from the NICE guideline on patient experience in adult NHS services.

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
they can readily converse in, including sign language - a carer, if that is what the person wants - communication aids (such as pictures, videos, symbols, large print, Braille, hearing loops) - evidence-based techniques for communication - additional time to understand and process information - environmental conditions that support communication, such as clear lighting, and minimal noise interference.	
1.1.6 If a person lacks the capacity to make a decision, the provisions of the Mental Capacity Act 2005 must be followed.	BF1, TLAPV3, GC consensus
1.1.7 Use plain language and personalise the communication approach to encourage and enable people to be actively involved in their care and support. If technical language or jargon has to be used, or complicated ideas are being discussed, take time to check that the person, or a carer who knows them well, understands what is being said.	BF1, V7, GC consensus
1.1.8 If a third party or advocate is supporting someone to give their views, ensure that enough time has been allowed for them to do it.	RQ4.7
1.1.9 Local authorities and service providers should work with people who use adult social care services and their carers as far as possible to co-produce: - the information they provide - organisational policies and procedures - staff training	GC consensus
Access to care	
1.1.10 Ensure that everyone with social care needs has access to services based on their needs, taking account of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation, and socio-	NICE Guideline on service user experience in adult mental health (recommendation 1.2.5), GC consensus, PA1

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
economic status or other aspects of their identity[18].	
1.1.11 Service providers should be aware of the cultural and religious needs of people who use services, and provide care and support that meets these needs. Examples include treatment choices, food choice and preparation, enabling people to dress in accordance with their culture or religion, personal grooming, or changes in timing of services around religious festivals – for example during Ramadan.	U4RQ1-3, V6, GC consensus
1.1.12 Commissioners and service providers should consider seeking advice from voluntary and community sector organisations such as disabled people's organisations and user-led organisations with expertise in equality and diversity issues to ensure that they can deliver services that meet the needs and preferences arising from: • gender, including transgender • sexual orientation and sexuality • disability • ethnicity • religious and cultural practices.	LDV4, U3RQ1-3, GC consensus
1.1.13 Ensure that people who use services and have caring responsibilities (for another adult or a child) receive support to access social care services, including information about childcare, or respite care[19].	NICE Guideline on service user experience in adult mental health (recommendations 1.1.18), GC consensus
Involving carers, families and friends	
1.1.14 Ask the person at the first point of contact whether and how they would like their carers, family, friends and advocates or other people of their choosing (for example, personal assistants) to be involved in discussions and decisions about their care and support, and follow their wishes. Review this regularly (at least every 6 to 12 months), or when requested[20].	NICE Guideline on service user experience in adult mental health (recommendation 1.1.14), LDV3

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[18] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

[19] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

[20] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
1.1.15 If the person would like their carers, family, friends and advocates involved[21]: - explain the principles of confidentiality, and how these are applied in the best interests of the person - discuss with the person and their carers, family, friends and advocates what this would mean for them - share information with carers, family, friends and advocates as agreed.	GC consensus
1.1.16 If a person lacks the capacity to make a decision about whether they wish their carers, family, friends and advocates to be involved, the provisions of the Mental Capacity Act 2005 must be followed.	GC consensus
1.2 Information	
1.2.1 In line with the Care Act 2014, local authorities must provide information about care and support services for people and their carers, including: - the types of care and support available - how to access care and support, including eligibility criteria - how to get financial advice about care and support - local safeguarding procedures and how to raise safeguarding concerns or make a complaint - rights and entitlements to assessments and care and support services - personal budgets and all the options for taking a personal budget – for example, local authority managed, Individual Service Fund or direct payment.	V9
1.2.2 Local authorities should ensure that information about care and support services is widely and publicly promoted – for example, in GP surgeries and community spaces as well as in specialist services such as homeless health centres.	GC consensus
1.2.3 Local authorities should provide information about the circumstances in which	LD1, GC consensus

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[21] NICE is developing a guideline on provision of support for adult carers (expected publication July 2019).

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
independent advocacy is available, in line with the Accessible Information Standard, and how to access it.	
1.2.4 Local authorities should provide comprehensive information about community resources and support, including voluntary organisations, user-led organisations and disabled people's organisations, and about available housing options.	V9
1.3 Care and support needs assessment and care planning	
1.3.1 Local authorities must, in line with the Care Act 2014, provide independent advocacy to enable people to participate in: • care and support needs assessment and • care planning and • the implementation process and review where they would otherwise have substantial difficulty in doing so.	RQ4.7, GC consensus
1.3.2 People who are supported by an independent advocate during care and support needs assessment and care planning should have enough time with their advocate: • for preparation before the assessment or care planning session • to ensure they have understood the outcome afterwards.	RQ4.7, GC consensus
Needs assessment	
1.3.3 Local authorities must ensure that care and support needs assessment under the Care Act 2014 focuses on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve in their day-to to-day life.	V4, GC consensus
1.3.4 Care and support needs assessment should:	V4, GC consensus

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
• involve the person and their carers in discussions and decisions about their care and support • take into account the person's personal history and life story • take a whole family approach • take into account the needs of carers • take into account the person's housing status, and where and who they want to live with • be aimed at promoting their interests and independence • be respectful of their dignity • be transparent in terms of letting people and their families and carers know how, when and why decisions are made • take into account the potential negative effect of social isolation on people's health and wellbeing[22].	
1.3.5 Local authorities should consider the person's preferences in terms of the time, date and location of the care and support needs assessment, and conduct the assessment face to face unless the person prefers a different method of assessment.	V4, GC consensus
1.3.6 Local authorities should ensure that: • the person is given details of the care and support needs assessment process and timescale at the start • the person is given details of the nature and purpose of the assessment • the person can have someone they choose to be present at the assessment • the assessment uses up-to-date information and documentation about the person • the person does not have to provide the same information in subsequent assessments.	V4, GC consensus
1.3.7 If a person who uses services has caring responsibilities, their care and support needs assessment should take account of this.	V4, GC consensus

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[22] This recommendation is adapted from the NICE guideline on home care.

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
In line with the Care Act 2014 they must also be offered a separate carer's assessment which should identify whether the person they care for is a carer themselves.	
1.3.8 Ensure that care and support needs assessment documentation about the person is accurate, up to date and well maintained and clarifies what assessed needs will be met and how.	V4, GC consensus
1.3.9 Offer the person a copy of any or all of the care and support needs assessment documentation. It should be shared with the person's carer if that is what they want.	V4, GC consensus
Care and support plans	
1.3.10 As part of care planning, consider identifying a named coordinator who is competent to: • act as the first point of contact for any questions or problems • contribute to the assessment process • liaise and work with the person, their families, carers and advocates • liaise and work with all health, social care and housing services involved with the person, including those provided by the voluntary and community sector • ensure that any referrals needed are made and are actioned.	V8, GC consensus
1.3.11 Build in flexibility to the care and support plan to accommodate changes to a person's needs and preferences – for example, by using direct payments (see recommendations 1.3.20 and 1.3.21) and agreeing a rolling 3-monthly budget so that people can use their money differently each week.	V4, V6, PA1, GC consensus
1.3.12 Local authorities and providers should ensure that the person's care and support plan includes clear information about what involvement from others (carers, family, friends and advocates) they want in their care and support, in line with the Care Act 2014. (See also recommendation 1.1.14)	RCB4
1.3.13 Ensure there is a transparent process for 'matching' care workers to people, taking into account:	Adapted from NICE guideline on home care (1.1.5), expert witness testimony on Personal Assistants

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
• the person's care and support needs and • the care workers' knowledge, skills and experience and • if possible and appropriate, both parties' interests and preferences[23].	
1.3.14 Ensure care workers are able to deliver care and support in a way that respects the person's cultural, religious and communication needs (see recommendation 1.1.11)[24].	Adapted from NICE guideline on home care
1.3.15 Care and support plans should record and address the specific needs of people in relation to equality and diversity issues[25].	Adapted from NICE Guideline on supporting people with dementia and their carers (1.1.1.3), V6
1.3.16 Care and support plans should be regularly reviewed, and include information on how and when these reviews should be carried out.	GC consensus
1.3.17 Care and support plans should include contingency planning and what to do in a crisis.	GC consensus
Personal budgets and direct payments	
1.3.18 The local authority must include the person's personal budget in their care and support plan, in line with the Care Act 2014.	GC consensus
1.3.19 Local authorities should: • inform people that they have the option to control their own funding to buy different sorts of care that meets their needs and chosen outcomes • provide information, advice and support so that the person can choose which option suits them best • give people the opportunity to exercise as much control as possible over the way they use any allocated funds to purchase a care package • inform people of the different payment systems available.	LDV1, TLAPV1, U6RQ1-3, V4
1.3.20 Local authorities should ensure that the direct payment process is:	V5, GC consensus

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[23] This recommendation is adapted from the NICE guideline on home care.
[24] This recommendation is adapted from the NICE guideline on home care.
[25] This recommendation is adapted from the NICE guideline on dementia.

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
• transparent about how the level of funding is decided • straightforward • accessible to all adults who receive social care and are eligible for local authority funding • reviewed periodically to make sure that it is meeting the objectives of the care and support plan. • able to meet the legal obligations of the person receiving that direct payment if they employ personal assistants.	
1.3.21 Local authorities should provide accessible information about direct payments, and peer support for people to use them. For example, this could be provided through user-led Centres for Independent Living.	V5, GC consensus
1.3.22 In line with the Care Act statutory guidance, local authorities should support local services that provide peer support. Their contribution could include: • financial support for local peer support services • providing physical space for people who give peer support to hold meetings with people who use services • helping peer support services with applying for grants for funding.	V5, GC consensus
Personal assistants	
1.3.23 If people have eligible needs that could be met by employing a personal assistant, the local authority should ensure that this option is discussed with the person and understood by them at the care and support planning stage.	LD7, TLAPV2, TLAPV3, V10, expert witness testimony on Personal Assistants, GC consensus
1.3.24 In line with the Care Act statutory guidance, local authorities should ensure that support is available for people employing personal assistants, and that they are told about where to get support with: • recruitment and retention of staff • their role and responsibilities as an employer (for example, payroll, terms and conditions, redundancy and contingency planning).	TLAPV3, expert witness testimony

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
1.3.25 Local authorities should consider the following to deliver support for people who employ personal assistants: • user-led Centres for Independent Living • other peer-support arrangements.	Expert witness testimony on Personal Assistants, GC consensus
1.3.26 In line with the market shaping duty in the Care Act 2014, local authorities should work with people who use social care services and their carers to enable access to personal assistants. For example, this could be done by providing training opportunities for people who are interested in becoming personal assistants.	Expert witness testimony on Personal Assistants
1.4 Providing care and support	
Care and support in all settings	
1.4.1 Service providers should foster a culture that enables practitioners to respect people's individual choices and preferences, in all settings where care is delivered, by: • co-producing policies and protocols with people who use services and their carers (see recommendation 1.1.9) • ensuring that there are open channels of communication between practitioners and people who use services • using the communication methods that suit the person, in line with the Accessible Information Standard • supporting people to take managed risks to achieve their goals – for example, taking part in hobbies or sports • ensuring that there are systems in place for reporting concerns or abuse • ensuring that practitioners have the time to build relationships with people • training and supporting practitioners to work in this way, and checking they are doing so.	BF3
1.4.2 Practitioners working in all settings where care and support is delivered should ask the person using services, their carers, family, friends and advocates what name they prefer to be called, and use their preferred name.	Adapted from NICE Guideline on service user experience in adult mental health (recommendation 1.1.3), BF1, V2, GC consensus
1.4.3 Practitioners working in all settings where care and support is delivered should take	BF4

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
time to build rapport with the people they support[26].	
1.4.4 Practitioners working in all settings where care and support is delivered should respond flexibly to the priorities a person might identify each day. For example, a person might ask a home care worker to spend more time helping them get dressed and less time on other tasks if they have a special event to attend.	RCB2, GC consensus
1.4.5 Day care and residential care providers should offer a choice of activities that are led by the person's needs, preferences and interests. Encourage people to take part by including activities that motivate them, support them to learn new skills and increase their level of independence. Recognise that preferences are not fixed and may change.	LD6, GC consensus
Continuity and consistency	
1.4.6 Service providers in all settings, with oversight by commissioners, should review staffing numbers and skill mix regularly to ensure that staffing and skill levels are sufficient.	RCB2, GC consensus
1.4.7 Commissioners and managers in all settings should ensure that there is continuity in care and support for people, including: • ensuring that all practitioners involved with the person's care and support are familiar with how that person likes support to be given • where possible, the same people are supporting the person • if the same staff are not available, ensuring there are good handover arrangements • ensuring that all staff supporting the person have similar levels of skills and competency • using the same independent advocate where possible.	V2, GC consensus
1.4.8 Providers and managers in all settings should ensure that:	V2, GC consensus

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[26] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
- people are informed in advance if staff will be changed and - any changes to care and support – for example when visits will be made, are negotiated with the person.	
1.4.9 Support people to make decisions about entering a new care setting or moving to a different setting. For guidance on transitions between particular settings, see the NICE guidelines on: - transition from children's to adults' services for young people using health or social care services - transition between inpatient hospital settings and community or care home settings for adults with social care needs - transition between inpatient mental health settings and community or care home settings.	BF1, V2, GC consensus, NICE guidelines on transition from children's to adults' services for young people using health or social care services, transition between inpatient hospital settings and community or care home settings for adults with social care needs and transition between inpatient mental health settings and community or care home setting.
1.4.10 To support collaborative working between services, commissioners and managers should consider putting the following in place: - a local policy for sharing information relevant to people's care within and between services in line with the Caldicott principles and the Health and Social Care (Safety and Quality) Act 2015 - joined-up policies, processes and systems.	V8, GC consensus
Personal care	
1.4.11 All practitioners providing personal care should ensure that personal care needs are responded to in a timely, appropriate and dignified manner in line with the person's wishes and their support plan – for example, making sure that people can go to the toilet when and how they want.	RCB6, GC consensus
Promoting positive relationships between people who use services	
1.4.12 Service managers and practitioners in day care and residential settings should promote a sense of community and mutual support – for example, by facilitating interactions and building social connections	BF5

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
between residents through activities such as social events.	
Residential settings	
1.4.13 Practitioners and managers in residential settings should: - ensure that the environment allows for people's preferences, self-expression and choice – for example, enabling people to have their own furniture and pictures - support people to have control over their own medicines where possible (see the NICE guideline on managing medicines in care homes) - deliver care and support in a personalised and friendly way - give people privacy, especially when delivering personal care - treat people with dignity and respect.	RCB1, RCB3, GC consensus
1.4.14 When designing residential services, providers should ensure that environments: - create space where practitioners and residents can have positive interactions - are welcoming to visits from family, friends, carers and advocates - are stimulating, while not creating additional challenges for residents, including those with sensory impairments or dementia (for example, if the layout is frequently changed or there is poor lighting) - enable positive risk taking (for example, being able to use outside spaces) - support residents' autonomy (for example, by adapting kitchen facilities for people with physical disability).	RCB9, BF4
1.4.15 Ensure that support in residential care is based on a good understanding of people's needs, including:	RCB1, RCB3

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
- providing practical and emotional support - accommodating speech and communication needs - helping people to maintain the personal relationships and friendships that are important to them - supporting people to take part in activities and social groups that they want to be involved in, both in the residential setting and in the community - viewing behaviour that challenges as a communication - providing access to community health teams and specialist support.	
1.4.16 Practitioners should support people to participate fully in tasks and activities by ensuring that: - the environment is conducive to their needs - they have access to the equipment they need (for example, hoists or recliner chairs).	BF6, BF7
1.4.17 Managers should ensure that practitioners are trained to support residents to use any equipment they need.	BF6, BF7
End of life support in residential settings	
1.4.18 Managers in residential settings should co-produce a policy on end-of-life care with people who use services and their carers. This should include information about: - documenting treatment and care preferences at the earliest opportunity (including formal ways of documenting preferences such as Lasting Power of Attorney for health and care decisions or advance statements of wishes and care preferences) - a named lead in the residential setting - training on supporting people and their carers at the end of their lives, tailored to different staff groups and updated regularly - ongoing support to enable practitioners to support people near the end of their	RCB4

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
lives, including creative ways of engaging people in discussions (for example, opportunities to discuss end of life care with peers).	
1.4.19 Managers in residential settings should consider making someone available who is independent and not part of the usual staff team to discuss end of life issues, for people who want to do this – for example, from an advocacy organisation.	RCB4
1.5 Staff skills and experience	
1.5.1 Have a transparent and fair recruitment and selection process that: • uses values-based interviews and approaches to identify the personal attributes and attitudes essential for a caring and compassionate workforce and • ensures that staff have the necessary language, literacy and numeracy skills to do the job[27].	NICE guideline on home care, recommendation 1.7.1
1.5.2 Local authorities should ensure that people undertaking needs and eligibility assessments have the knowledge and skills to carry out assessments as described in recommendations 1.3.3 to 1.3.9.	GC consensus
1.5.3 Service providers should consider involving people who use services and their carers ('experts by experience') in the recruitment and training of staff. For example: • being on interview panels • contributing to development and delivery training • helping to develop job descriptions • supporting and training others to be experts by experience.	RCB7, GC consensus
1.5.4 Consider providing opportunities for practitioners to learn from the personal experiences of all people who use services, in all settings where care is provided. This could be through:	BF7

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[27] This recommendation is adapted from the NICE guideline on home care.

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
• forums within residential and day care services • audit, planning and evaluation of services • practitioners being mentored by people who use services.	
1.5.5 Service providers should ensure that practitioners are aware of the local arrangements for, and understand the function of, other services that they may need to work with, such as other health and social care service providers and services provided by the voluntary sector.	BF7
1.5.6 Service providers should provide opportunities for practitioners to take part in interprofessional learning and development.	BF7
1.5.7 Service providers should ensure that practitioners are able to use any equipment or devices people need – for example hearing aid loops.	BF7, GC consensus
1.5.8 Service providers should ensure that practitioners are aware of issues relating to information sharing and confidentiality.	GC consensus
1.6 Involving people in service design and improvement	
1.6.1 Local authorities must provide opportunities for people who use services to be involved if they want to in strategic decision-making about services, not just their own care and support, in line with the Local Government and Public Involvement in Health Act 2007. This should include involving people in: • decisions about the way services are commissioned, run and are governed and • checking that the service is delivering quality care and support.	BF2, GC consensus
Using people's views to improve services	
1.6.2 All research into the views of people using care and support and their carers should be co-produced at all stages, including the research design, how it is carried out, and any resulting actions (for example, developing or refining quality indicators, developing monitoring tools or identifying gaps in services).	RQ4.1, RQ4.2
1.6.3 Commissioners and service providers should communicate clearly the outcome that	RQ4.1

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
any exercise to collect people's views is aiming to achieve and what will be done as a result.	
1.6.4 Commissioners and service providers should consider using a range of approaches to gather views and experiences (for example focus groups, interviews or observation in addition to surveys), and use evidence from a range of sources. This could include: • the lived experiences of people who use services • information from third sector and voluntary organisations that represent people who use social care services – for example, Healthwatch • existing sources of information, such as complaints.	Expert witness testimony on approaches to gathering views and experiences
1.6.5 Local authorities should consider gathering and analysing evidence on people's experience of services in collaboration with other health and social care organisations serving the same populations to reduce duplication and ensure economies of scale.	U1Q4
1.6.6 Organisations conducting research should consider from the outset how to ensure that all groups are able to participate, including people who may lack capacity and people with different communication needs. This may involve adapting different research methods (see recommendation 1.6.4) or providing materials in a range of formats. If the participation or response rate for a particular group is low, the organisations should take action to improve it. This could include investigating what specific communication or cultural reasons may account for the low response and adapting materials or response formats to better suit that group.	RQ4.6, expert witness testimony on approaches to gathering views and experiences
1.6.7 Service providers should seek the views of people who use services about the extent to which the things that are important to them are being addressed. This should be done in such a way that the person feels safe to express their views, even if these are critical (for example, a care home resident may not want to give feedback directly to the manager).	BF3, GC consensus
1.6.8 Organisations or individuals conducting research or seeking feedback from people who	RQ4.6

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
use services should ensure that independent advocacy is available and offered when: • this would help someone to take part or • the person expresses a preference to use advocacy.	
1.6.9 Service providers should consider employing people who use services to monitor people's experience of health and social care services, including conducting research. This could be done by: • offering training to 'experts by experience' on how to conduct interviews with people who use services, including supporting them in applying ethical principles such as informed consent and confidentiality • paying them to undertake exit interviews with people who have recently left a service or moved to another service[28].	Adapted from NICE Guideline on service user experience in adult mental health (recommendation 1.1.21)
1.6.10 Commissioners and providers should ensure that the results of research with people are used to inform improvements to services.	U2Q4, GC consensus
1.6.11 Commissioners and service providers should make available the results of research with people who use services, using approaches developed with people who use services. This should include: • publishing the results • giving feedback directly to people who took part • making public how they have responded to people's feedback – for example, by using 'you said, we did' tables or case studies.	RQ4.1, U2Q4, GC consensus
Survey research	
1.6.12 Consider using existing validated surveys before deciding to develop a new survey.	RQ4.2, GC consensus
1.6.13 Local authorities should analyse the characteristics of people who did not or could not respond to surveys and:	Expert witness testimony on approaches to gathering views and experiences, GC consensus

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[28] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
• report on any under-represented groups in their published report of the survey and seek to understand the reasons for this • develop ways to address these gaps in the future – for example, by considering alternative modes of response, such as a telephone response line • ensure that information about under-represented groups is fed back to the survey designers.	
1.6.14 Local authorities should ensure that people in their organisations who are responsible for interpreting and implementing survey findings have the necessary skills and capacity.	GC consensus

3.9 Evidence to recommendations

Topic/section heading	**Overarching principles: Knowing the person as an individual and enabling people to take decisions about their care**
Recommendations	1.1.1 Recognise that each person who uses services is an individual. Use each person's self-defined strengths, preferences, aspirations and needs as the basis on which to provide care and support to live an independent life[29]. 1.1.2 Support people to maintain their independence. This means finding out what people want from their life, and providing the support and assistance they need to do this[30]. 1.1.3 Respect people's right to make their own decisions, and do not make assumptions about people's capacity to be in control of their own care and support (for example, if the person is severely disabled). 1.1.4 Actively involve the person in all decisions that affect them. 1.1.5 Provide support to people, if they need it, to express their views, preferences and aspirations in relation to their care and support. Identify and record how the person wishes to communicate and if they have any communication needs (in line with the Accessible Information Standard). This could include: • advocacy support • an independent interpreter (that is, someone who does not have a relationship with the person or the services they are using) to enable people to communicate in a language they can readily converse in, including sign language • a carer, if that is what the person wants • communication aids (such as pictures, videos, symbols, large print, Braille, hearing loops) • evidence-based techniques for communication • additional time to understand and process information • environmental conditions that support communication, such as clear lighting, and minimal noise interference. 1.1.6 If a person lacks the capacity to make a decision, the provisions of the Mental Capacity Act 2005 must be followed. 1.1.7 Use plain language and personalise the communication approach to encourage and enable people to be actively involved in their care and support. If technical language or jargon has to be used, or complicated ideas are being discussed, take time to check that the person, or a carer who knows them well, understands what is being said. 1.1.8 If a third party or advocate is supporting someone to give their views, ensure that enough time has been allowed for them to do it.

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[29] This recommendation is adapted from the NICE guideline on patient experience in adult NHS services.

[30] This recommendation is adapted from the NICE guideline on patient experience in adult NHS services.

	1.1.9 Local authorities and service providers should work with people who use adult social care services and their carers as far as possible to co-produce: • the information they provide • organisational policies and procedures • staff training.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services? 2. For people who use adult social care services, what are the barriers related to improving their experience of care? 3. For people who use adult social care services, what would help improve their experience of care?
Quality of evidence	The evidence for these recommendations was taken from the reviews of user views about aspects of experience of using adult social care services that are positive or valued; user views about barriers related to improving their experience of care; and user views about what would help improve their experience of care. For recommendation 1.1.1 the Guideline Committee discussion focused on recommendation 1.1.1 from the NICE guideline on patient experience in adult NHS services. The patient experience guideline was identified at an early stage as being of particular relevance to this guideline. Recommendation 1.1.2 was based on the review of the NICE guideline on patient experience in adult NHS services (recommendation 1.2.10). It was also supported by 2 evidence statements: LD2 (1 poor, 1 medium quality UK study) and LD3 (1 medium quality UK study). For recommendations 1.1.3, 1.1.4 and 1.1.6 on enabling people to take decisions about their care, evidence was based on 2 evidence statements. Evidence statement BF1 consisted of 3 high and 2 medium quality UK studies, while the second evidence statement TLAP V3 was based on 3 videos of low quality. Recommendation 1.1.5, which was about providing support to people in terms of advocacy, independent interpreters, communication aids and evidence-based techniques, was based on 4 evidence statements: LD1 (2 medium and 1 low quality UK study), LD4 (2 medium quality UK studies) RQ4.7 (1 medium quality study) and V1 (2 high and 2 medium quality UK studies). Recommendation 1.1.7, about the use of plain language and communication to encourage and enable people to be actively involved in their care and support, was based on 2 evidence statements BF1 (3 high and 2 medium quality UK studies) and V7 (1 high quality and 3 medium quality UK studies). Recommendation 1.1.8 about time limits to advocacy interviews was a barrier to enabling people to express their wishes was based on RQ4.7 (1 medium quality mixed methods study).
Economic considerations	Although no economic evidence was available to inform these recommendations, the Guideline Committee was mindful of potential costs and resource use when making the

	recommendations. The Committee noted that many of the working practices being recommended here are aligned with statutory requirements, and therefore local organisations should be working towards them already. For example, the Care Act 2014 explicitly shifted the focus of services towards meeting needs, with the Care Act statutory guidance stating that 'the concept of meeting needs recognises that everyone's needs are different and personal to them'. The view of the Committee was that working in a personalised way to meet needs and support independence (recommendations 1.1.1, 1.1.2, 1.1.3 and 1.1.4) was therefore aligned to how organisations should already be working, and should not require significant additional resources. The Committee also considered the potential resource implications of recommendations 1.1.5 and 1.1.8 on supporting communication and allowing sufficient time for advocacy interviews. Again, it was the view of the Committee that this is required good practice within the Care Act 2014, Equality Act 2010 and Accessible Information Standard, and so should be aligned to what organisations are already undertaking. In relation to co-production (recommendation 1.1.9), the Committee noted that a co-production approach is an element of good practice as recommended in the statutory guidance in the Care Act 2014. It was acknowledged that additional time and financial resources can be required to implement meaningful co-production, but that this produced benefits in terms of the quality and fitness for purpose of the outputs produced.
Evidence statements – numbered evidence statements from which the recommendations were developed	BF1 (recommendations 1.1.3, 1.1.4, 1.1.6, 1.1.7) LD1 (recommendation 1.1.5) LD2 (recommendation 1.1.2) LD3 (recommendation 1.1.2) LD4 (recommendation 1.1.5) RQ4.7 (recommendation 1.1.5) TLAPV3 (recommendations 1.1.3, 1.1.4, 1.1.6) V1 (recommendation 1.1.5) V7 (recommendation 1.1.7) RQ4.7 (recommendation 1.1.8)
Other considerations	Recommendation 1.1.1 was adapted from the NICE guideline on patient experience in adult NHS services. The patient experience guideline was identified at an early stage as being of particular relevance to this guideline, and was reviewed by the Committee. The Committee highlighted the importance of having a recommendation in this guideline about respecting the person as an individual. This personalised approach was also thought to be important in terms of ensuring that the full range of diversity and equality issues are addressed. Discussion emphasised the need to make the language relevant to our population (for example, using the term 'people' rather than patients). Recommendation 1.1.2 was adapted from the NICE guideline on patient experience in adult NHS services, (recommendation 1.2.10). The recommendation was reworded to make it applicable to users of adult social care

	Recommendations 1.1.3, 1.1.4 and 1.1.6 were based on evidence statements BF1 and TLAPV3. Recommendation 1.1.3 was thought to be particularly important for people with more severe or complex needs (a group highlighted through the Equality Impact Assessment). For recommendation 1.1.4, the Guideline Committee's professional and personal experience particularly highlighted the importance of people being involved in discussions about transitions between services. Recommendation 1.1.5 addressed the needs of people who may lack capacity, who had again been identified as requiring particular consideration through the Equality Impact Assessment. Recommendation 1.1.5 about supporting people to express their views, preferences and aspirations in relation to their care and support was based on evidence statements LD1, LD4, RQ4.7 and V1. The evidence included: a lack of support to listen to the complaints of residents with learning disabilities living in supported accommodation; time limits to advocacy interviews being a barrier to delivering person-centred care; and language being a significant barrier to receiving and accessing services. The Guideline Committee had wide-ranging discussions which included: the need to deal with people's complaints; acknowledgement of the significance of advocacy; and an awareness that certain groups such as people with dementia and people with learning disabilities are excluded from participating in local authority surveys. The Guideline Committee agreed that this recommendation should be broadened to all groups and settings. Additional detail on how to support people with different communication needs to express their views, preferences and aspirations by following the guidance set out in the Accessible Information Standard was added based on Guideline Committee consensus following stakeholder feedback. Recommendation 1.1.7 about the use of plain language and communication to encourage and enable people to be actively involved in their care and support was based on evidence statements BF1 and V7. Guideline Committee discussion included recognising the importance of choice and control in relation to evidence statement V7, and that being able to understand what is being communicated about your care was an important part of this. Recommendation 1.1.8 was based on RQ4.7, which found that time limits to advocacy interviews is a barrier to enabling people to express their wishes. Again, the Committee considered the resource implications of ensuring sufficient time with advocates. However, this was balanced against the potential for particular groups, particularly people with learning disabilities or people who may lack capacity, to be excluded from giving their views and experiences in the absence of support. Recommendation 1.1.9 was a consensus recommendation based on the Guideline Committee's professional and personal experience that co-production of all aspects of service design and delivery led to a better quality of service, and improved experiences for people who use services. The principle of co-production was thought to be relevant across many aspects of care, and so was made an overarching principle. In terms of the

	potential resource impact of this recommendation, it was recognised that co-production is also a recommended approach within the Care Act statutory guidance.

Topic/section heading	**Overarching principles: Access to care**
Recommendations	1.1.10 Ensure that everyone with social care needs has access to services based on their needs, taking account of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation, and socio-economic status or other aspects of their identity[31]. 1.1.11 Service providers should be aware of the cultural and religious needs of people who use services, and provide care and support that meets these needs. Examples include treatment choices, food choice and preparation, enabling people to dress in accordance with their culture or religion, personal grooming, or changes in timing of services around religious festivals – for example, during Ramadan. 1.1.12 Commissioners and service providers should consider seeking advice from voluntary and community sector organisations such as disabled people's organisations and user-led organisations with expertise in equality and diversity issues to ensure that they can deliver services that meet the needs and preferences arising from: • gender, including transgender • sexual orientation and sexuality • disability • ethnicity • religious and cultural practices. 1.1.13 Ensure that people who use services and have caring responsibilities (for another adult or a child) receive support to access social care services, including information about childcare, or respite care[32].
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services? 2. For people who use adult social care services, what are the barriers related to improving their experience of care? 3. For people who use adult social care services, what would help improve their experience of care?

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[31] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

[32] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

	4. What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?
Quality of evidence	The evidence for the need for cultural and personal values to be respected when delivering care and used to tailor care to meet the specific needs of individuals was based on: evidence statement V6 comprising 1 high quality and 1 medium quality UK study, and evidence statement U4RQ1-3 comprising 1 high and 1 medium quality UK study. Evidence on responding to the needs of particular groups of service users was provided in evidence statement U3RQ1-3 comprising 1 high, 1 medium and 1 low quality UK study, and evidence statement LDV4 comprising 1 poor quality UK study (video evidence). The evidence for ensuring that people who use services and are caring for children to receive support to access social care services was based on evidence statement V6 consisting of 1 high quality and 1 medium quality UK study.
Economic considerations	Although no economic evidence was available to inform these guideline recommendations, the Guideline Committee was mindful of potential costs and resource use when making the recommendations. In particular, the Committee considered the resource implications of seeking advice from the voluntary and community sector (recommendation 1.1.12). However, the view of the Committee was that this would entail less use of resources than trying to build up specialist knowledge in relation to a range of groups within individual organisations.
Evidence statements – numbered evidence statements from which the recommendations were developed	LDV4 (recommendation 1.1.12) U3RQ1-3 (recommendation 1.1.12) U4RQ1-3 (recommendation 1.1.11) V6 (recommendation 1.1.11)
Other considerations	Recommendation 1.1.10 was adapted from the NICE guideline on service user experience in adult mental health, which was identified at the scoping stage as being of particular relevance to this guideline. The Guideline Committee considered the principle of equality of access to be relevant to social care services. The wording of the recommendation was adapted to make it specific to this population group and also to include all protected characteristics from the Equality Act 2010. This was also supported by evidence from 1 study of the views and experiences of LGBTQI people's experiences of employing personal assistants in evidence statement PA1. The Committee considered the resource impact of this recommendation. The view of the Committee was that this was not entail additional resource as the recommendation did not mean that more people should have access to services, but that provision of services should be equitable. Recommendation 1.1.11 was based on U4RQ1-3 and V6, which included evidence about the need for cultural and personal values

	to be respected when delivering care, and to tailor care to meet the specific needs of individuals. Specific examples about how to meet cultural and religious needs were based on the Guideline Committee's own professional and personal experience. Recommendation 1.1.12 was based on LDV4 and U3RQ1-3, which included evidence about the importance of being sensitive to the needs of lesbian, gay, bisexual and transgender people who use services. The view of the Committee was that there are a range of groups that would need particular consideration by services. The Guideline Committee's professional and personal experience suggested that that voluntary sector organisations can play an important role in helping service providers to understand and accommodate diversity. This also aimed to recognise that achieving the requirements of recommendation 1.1.12 can be challenging in practice, and provide a mechanism for doing this. Recommendation 1.1.13 was adapted from recommendation 1.1.18 in the NICE guideline on service user experience in adult mental health, which was identified at the scoping stage as being of particular relevance to this guideline. The Guideline Committee amended the wording to reflect a social care population. Detail on involving disabled people's organisations and user-led organisations in achieving this was based on Guideline Committee consensus following stakeholder comments on this recommendation.

Topic/section heading	**Overarching principles: Co-production and involving carers, families and friends**
Recommendations	1.1.14 Ask the person at the first point of contact whether and how they would like their carers, family, friends and advocates or other people of their choosing (for example, personal assistants) to be involved in discussions and decisions about their care and support, and follow their wishes. Review this regularly (at least every 6 to 12 months), or when requested[33]. 1.1.15 If the person would like their carers, family, friends and advocates involved[34]: • explain the principles of confidentiality, and how these are applied in the best interests of the person • discuss with the person and their carers, family, friends and advocates what this would mean for them • share information with carers, family, friends and advocates as agreed. 1.1.16 If a person lacks the capacity to make a decision about whether they wish their carers, family, friends and advocates to be involved, the provisions of the Mental Capacity Act 2005 must be followed.

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[33] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

[34] NICE is developing a guideline on provision of support for adult carers (expected publication July 2019).

Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services?
Quality of evidence	Recommendation 1.1.14 about involving carers, family and friends was adapted from the NICE guideline on service user experience in adult mental health (recommendation 1.1.14). It was also supported by 2 poor quality UK studies (video evidence).
Economic considerations	Although no economic evidence was available to inform these guideline recommendations, the Guideline Committee was mindful of potential costs and resource use when making the recommendations.
Evidence statements – numbered evidence statements from which the recommendations were developed	LDV3 (recommendation 1.1.14)
Other considerations	Recommendation 1.1.14 was adapted from the NICE guideline on service user experience in adult mental health (recommendation 1.1.15), which was identified at the scoping stage as being of particular relevance to this guideline. The Committee adapted the wording of the recommendation, and the frequency with which this should be reviewed, to reflect a social care population. The Committee talked about the importance of making sure carers are not the sole 'voice' of people using services but the need to always start with the person who is using services. The Committee emphasised that it is important to give people choice about whether their family members and friends are involved in their care and support. This recommendation was also supported by video evidence about the importance of supporting the families of people with learning disabilities The Guideline Committee added further detail that reviews should take place when they are requested, not only at pre-determined time points following stakeholder consultation. Recommendation 1.1.15 and 1.1.16 were consensus recommendations, based on the Guideline Committee's professional experience. Again, the Committee was mindful of balancing the involvement of carers, family and friends with the person's right to independence and privacy. Additional detail that the forthcoming NICE guideline on provision of support for adult carers should be followed if the person wants their carers involved in their care was based on committee consensus after stakeholder consultation.

Topic/section heading	**Information**

Recommendations	1.2.1 In line with the Care Act 2014, local authorities must provide information about care and support services for people and their carers, including: • the types of care and support available • how to access care and support, including eligibility criteria • how to get financial advice about care and support • local safeguarding procedures and how to raise safeguarding concerns or make a complaint • rights and entitlements to assessments and care and support services • personal budgets and all the options for taking a personal budget – for example, local authority managed, Individual Service Fund or direct payment. 1.2.2 Local authorities should ensure that information about care and support services is widely and publicly promoted – for example, in GP surgeries and community spaces as well as in specialist services such as homeless health centres. 1.2.3 Local authorities should provide information about the circumstances in which independent advocacy is available, in line with the Accessible Information Standard, and how to access it. 1.2.4 Local authorities should provide comprehensive information about community resources and support, including voluntary organisations, user-led organisations and disabled people's organisations, and about available housing options.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services?
Quality of evidence	The evidence for these recommendations was taken from the review of user views about aspects of experience of using adult social care service that are positive or valued. The recommendation about providing people with information in line with the Accessible Information Standard comes from 2 evidence statements, which comprise 6 high quality and 5 medium quality UK studies. The evidence about local authorities needing to provide comprehensive information on care and support comes from 1 evidence statement consisting of 3 high quality and 5 medium quality UK studies. The recommendation about local authorities providing information on independent advocacy comes from 1 evidence statement containing 2 medium quality UK studies and 1 low quality UK study about learning disabilities. The recommendation about local authorities needing to provide information on local support groups comes from 3 high quality and 5 medium quality UK studies found in 1 evidence statement.
Economic considerations	Although no economic evidence was available to inform these guideline recommendations, the Guideline Committee was mindful of potential costs and resource use when making the

	recommendations. In relation to provision of information, the Committee noted that many of the recommendations were requirements of the Care Act 2014, and so should not represent significant additional investment above implementing the requirements of the Act. Exceptions to this were the provision of information about how to access advocacy (not just when advocacy should be available, which is a requirement of the Act). However, it was the view of the Committee that this information could be provided at the same time, and so would not represent an additional cost. Providing information about local voluntary groups is also not strictly a provision of the Care Act, but again could be provided using the same channels as other forms of information provision.
Evidence statements – numbered evidence statements from which the recommendations were developed	LD1 (recommendation 1.2.3) V9 (recommendations 1.2.1, 1.2.4)
Other considerations	Recommendation 1.2.1 was developed from evidence statement V9 which described the problem with information being lacking, inaccessible, inconsistent and sub-standard, which was particularly challenging for people with newly acquired impairments or multiple sensory impairments. The research also referred to eligibility for care packages and financial entitlements. The Guideline Committee extrapolated this evidence to include all population groups. The Committee's view was also that it was particularly important that individuals know about their right to be assessed for services. The recommendation also emphasised aspects of Section 4 of the Care Act 'Providing information and advice' including the right to financial advice and choice of types of care and support available. The Guideline Committee added further detail on letting people know about their eligibility for services in advance, based on comments from the stakeholder consultation. The Guideline Committee also added detail in this recommendation that people should know about all the options available in order to choose the best option for them. The Guideline Committee added reference to safeguarding and complaints processes based on Committee consensus following stakeholder feedback. Recommendation 1.2.2 was a consensus recommendation, based on the Guideline Committee's professional and personal experience that people being able to access services is dependent on having widely available information - not just information available to those already 'in the system'. Stakeholder comments noted that not all people who are eligible for services are in contact with formal services. The Guideline Committee added further detail on where to promote care and support services that could reach people not in contact with services. Recommendation 1.2.3 was based on evidence statement LD1, which was specific to people with learning disabilities. The Guideline Committee said that assumptions are made about

	people with complex needs based on their presentation, for example learning disabilities, and they get ignored - there is a need to understand the holistic needs of a person and their life story. Reflecting on the findings of the evidence, the Committee agreed that there needs to be a clear process for dealing with complaints. Personalisation, dignity, and being informed of one's rights are essential. Advocacy was seen as significant, with consensus that it is important to broaden the recommendation out as it relates to other groups who may require advocacy, such as people with dementia, or those who do not have family and friends who can advocate on their behalf, or do not wish them to do so. Recommendation 1.2.4 was based on evidence statement V9, which includes users' experiences of using mainstream, community-based support services and how this contrasts with disabled people's experiences of user-led services, which were seen as significantly more responsive to people's needs. The evidence showed that there was a problem with the lack of information about the benefits of user-controlled services and the organisations providing them. The professional and personal experience of the Guideline Committee about the importance of helping people to access local support groups and voluntary organisations was also crucial in shaping this recommendation. Based on stakeholder comments, the Guideline Committee added further detail on user-led organisations and disabled people's organisations, as examples of support groups to link to.

Topic/section heading	**Care and support needs assessment and care planning**
New recs	1.3.1 Local authorities must, in line with the Care Act 2014, provide independent advocacy to enable people to participate in: • care and support needs assessment and • care planning and • the implementation process and review where they would otherwise have substantial difficulty in doing so. 1.3.2 People who are supported by an independent advocate during care and support needs assessment and care planning should have enough time with their advocate: • for preparation before the assessment or care planning session • to ensure they have understood the outcome afterwards. 1.3.3 Local authorities must ensure that care and support needs assessment under the Care Act 2014 focuses on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve in their day-to-day life. 1.3.4 Care and support needs assessment should:

	- involve the person and their carers in discussions and decisions about their care and support - take into account the person's personal history and life story - take a whole family approach - take into account the needs of carers - take into account the person's housing status, and where and who they want to live with - be aimed at promoting their interests and independence - be respectful of their dignity - be transparent in terms of letting people and their families and carers know how, when and why decisions are made - take into account the potential negative effect of social isolation on people's health and wellbeing[35]. 1.3.5 Local authorities should consider the person's preferences in terms of the time, date and location of the care and support needs assessment, and conduct the assessment face-to-face unless the person prefers a different method of assessment. 1.3.6 Local authorities should ensure that: - the person is given details of the care and support needs assessment process and timescale at the start - the person is given details of the nature and purpose of the assessment - the person can have someone they choose to be present at the assessment - the assessment uses up-to-date information and documentation about the person - the person does not have to provide the same information in subsequent assessments. 1.3.7 If a person who uses services has caring responsibilities, their care and support needs assessment should take account of this. In line with the Care Act 2014 they must also be offered a separate carer's assessment which should identify whether the person they care for is a carer themselves. 1.3.8 Ensure that care and support needs assessment documentation about the person is accurate, up to date and well maintained and clarifies what assessed needs will be met and how. 1.3.9 Offer the person a copy of any or all of the care and support needs assessment documentation. It should be shared with the person's carer if that is what they want.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services?

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[35] This recommendation is adapted from the NICE guideline on home care.

Quality of evidence	The evidence for these recommendations was taken from the review of user views about aspects of experience of using adult social care service that are positive or valued. Recommendations 1.3.1 to 1.3.9 were based on evidence statement V4, which contained a good amount of medium level quality evidence that service delivery needs to respect people's desire for independence and plan around it. This evidence statement was based on 9 UK studies, of which 3 were rated high quality and 6 were rated medium quality.
Economic considerations	Although no economic evidence was available to inform these guideline recommendations, the Guideline Committee was mindful of potential costs and resource use when making the recommendations. The Committee noted that the provision of advocacy, which has a potential resource impact, is a legal requirement within the Care Act 2014. With regard to recommendation 1.4.5 about the timing, location and medium of the assessment, this is aligned with the provisions of the statutory guidance within the Care Act 2014. The Guideline Committee noted the potential resource impact of having face-to-face needs assessment, but also noted that this is one of the options available within the Care Act 2014.
Evidence statements – numbered evidence statements from which the recommendations were developed	V4 (recommendations 1.3.3, 1.3.4, 1.3.5, 1.3.6, 1.3.7, 1.3.8, 1.3.9) RQ4.7 (recommendation 1.3.1, 1.3.2)
Other considerations	Recommendations 1.3.1 and 1.3.2 were based on RQ4.7 about access to advocacy, and having sufficient time with an advocate. Recommendation 1.3.1 highlighted the statutory duty within the Care Act 2014 to provide advocacy. Although the Committee noted that there is already a duty to provide this, they thought access to advocacy was very important to people's experience of services, and the extent to which assessment and care planning processes are able to fully understand a person's individual needs and preferences. Recommendation 1.3.2 drew on Guideline Committee expertise and experience in the use of advocacy. Following stakeholder consultation, the Guideline Committee noted that advocacy involvement should be at every stage of the process to be effective, and revised this recommendation to include assessment, planning, implementation and review stages. Recommendations 1.3.3 to 1.3.9 were developed from evidence statement V4, which contained a good amount of medium level quality evidence that service delivery needs to respect people's desire for independence and plan around it. The Guideline Committee identified that the key mechanism for this was in the assessment and care and support planning process. The Committee thought that the way this process was undertaken was key in ensuring that it provided a good experience and also achieved the required outcomes of planning for independence. The recommendations were also compared for consistency with

	the guidance in the Care Act 2014, to ensure there were no contradictory recommendations. Recommendations 1.3.3, 1.3.4, 1.3.5 and 1.3.6 were also based on the Guideline Committee's professional and personal knowledge of some of the challenges of care and support needs assessment and the characteristics of a good assessment, including: the need to let the user feel in control and be able to set goals; avoidance of repeat assessments; need for advocacy, including that an advocate should be available before the initial assessment; the need to get a good history of the service user; the need for the social worker to be honest about what is actually available and feasible; and phone assessments not providing a full picture. Following stakeholder consultation, the recommendation was revised to include detail on taking a whole life approach to care and support planning, recognising the important role that carers and families play. Housing was added as an important part of someone's care and support needs. The Guideline Committee agreed that recommendation 1.3.7 should be a stand-alone recommendation, in recognition of the fact that some people who use services also have caring responsibilities. This group had also been identified in the Equality Impact Assessment as being at risk of poor care. Recommendations 1.3.8 and 1.3.9 about assessment documentation were originally one recommendation, but the Guideline Committee split these into two to distinguish between the quality of the assessment documentation in 1.3.8 (the Committee thought this is important, and noted that it is supported by the Data Protection Act) and the duty for assessors to provide service users with a copy of their assessment documentation (recommendation 1.3.9). This latter recommendation was formulated in light of discussions about the extensive information about service users that is generated on the system and in case notes, not all of which gets sent out for practical reasons. The Committee also considered evidence in relation to the experience of people with learning disabilities of the assessment process (LD5), but did not make a specific recommendation based on this.

Topic/section heading	**Assessment and care planning: Care and support plans**
New recs	1.3.10 As part of care planning, consider identifying a named coordinator who is competent to:

	• act as the first point of contact for any questions or problems • contribute to the assessment process • liaise and work with the person, their families, carers and advocates • liaise and work with all health, social care and housing services involved with the person, including those provided by the voluntary and community sector • ensure that any referrals needed are made and are actioned. 1.3.11 Build in flexibility to the care and support plan to accommodate changes to a person's priorities, needs and preferences – for example, by using direct payments (see recommendations 1.3.20 and 1.3.21) and agreeing a rolling 3-monthly budget so that people can use their money differently each week. 1.3.12 Local authorities and providers should ensure that the person's care and support plan includes clear information about what involvement from others (carers, family, friends and advocates) they want in their care and support, in line with the Care Act 2014. (See also recommendation 1.1.14.) 1.3.13 Ensure there is a transparent process for 'matching' care workers to people, taking into account: • the person's care and support needs and • the care workers' knowledge, skills and experience and • if possible and appropriate, both parties' interests and preferences[36]. 1.3.14 Ensure care workers are able to deliver care and support in a way that respects the person's cultural, religious and communication needs (see recommendation 1.1.11)[37]. 1.3.15 Care and support plans should record and address the specific needs of people in relation to equality and diversity issues[38]. 1.3.16 Care and support plans should be regularly reviewed, and include information on how and when these reviews should be carried out. 1.3.17 Care and support plans should include contingency planning and what to do in a crisis.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services? 2. For people who use adult social care services, what are the barriers related to improving their experience of care? 3. For people who use adult social care services, what would help improve their experience of care?

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[36] This recommendation is adapted from the NICE guideline on home care.
[37] This recommendation is adapted from the NICE guideline on home care.
[38] This recommendation is adapted from the NICE guideline on dementia.

Quality of evidence	The evidence for these recommendations was taken from the reviews of user views about aspects of experience of using adult social care service that are positive or valued; user views about barriers related to improving their experience of care; and user views about what would help improve their experience of care. The evidence for the ‘named co-ordinator’ and ‘collaborative working’ recommendation (recommendation 1.3.10) came from 1 evidence statement consisting of 1 high quality and 2 medium quality UK studies. The evidence on building enough flexibility into the care plan to accommodate changes to a person’s needs and preferences (recommendation 1.3.11) was based on 9 studies, 3 rated high quality and 6 rated medium quality. A further study, rated high quality, identified in evidence statement V6, was also fundamental in shaping this recommendation. The evidence for recommendation 1.3.12 that local authorities should ensure that a person’s care and support plan makes explicit what involvement he or she wants from others in their care plan is provided by 1 evidence statement about end of life care and is comprised of 3 UK studies, 2 of which are medium quality and 1 which is high quality. These studies are all based in a care home setting. Recommendation 1.3.13 and recommendation 1.3.14 were adapted from the NICE guideline on home care. The evidence about the need to address equality and diversity issues in care plans (recommendation 1.3.15) is provided by 1 high quality and 2 medium quality UK studies.
Economic considerations	Although no economic evidence was available to inform these guideline recommendations, the Guideline Committee was mindful of potential costs and resource use when making the recommendations. The view of the Committee was that these recommendations related largely to undertaking existing activities in a slightly different way, and so should not have a significant resource impact. The Guideline Committee noted the potential resource impact of recommendation 1.3.10 if this role does not already exist within a local authority area. However, the Committee noted that that a ‘single named contact’ is also specified in the guidance supporting the Care Act 2014, so this should be in the process of being implemented already.
Evidence statements – numbered evidence statements from which the recommendations were developed	V8 (recommendation 1.3.10) PA1 (recommendation 1.3.15) RCB4 (recommendation 1.3.12) V4 (recommendation 1.3.11) V6 (recommendation 1.3.11, 1.3.15)
Other considerations	Recommendation 1.3.10 was based on evidence statement V8, which related to fragmentation of services. The Guideline Committee discussed consistent evidence about service fragmentation and incoherence. This was thought to be a particular issue for people living in unstable situations or with no fixed address. The Committee’s view was that this issue could be

	addressed by having a single named co-ordinator. Additional detail was added to this recommendation that named coordinators should also work with the housing sector, based on Guideline Committee consensus following stakeholder consultation. Recommendation 1.3.11 was based on evidence statement V4 about the need for service delivery to respect people's desire for independence and plan around it, V6 about tailoring delivery and PA1 in relation to personal assistants. The Guideline Committee discussed the fact that a key opportunity to discuss and plan for independence, and to tailor services, was through the assessment and care planning process, and so focused their recommendations on these processes. In particular, the Rainbow Ripples and Butler (2006) study in evidence statement V6 highlighted the importance of flexibility to people who use services. The Committee discussed mechanisms in the care planning process that could support independence and flexibility. Reference to the example of achieving flexibility through use of a rolling budget was based on the Guideline Committee's professional and personal experience of services. Recommendation 1.3.12 was based on evidence statement RCB4, which drew on research about different people's involvement in end-of-life care. However, the Guideline Committee thought it was appropriate to extrapolate this evidence to make a broader recommendation that related to involvement of family members and others more broadly. Again, the group noted that a key mechanism for achieving this should be as part of the care planning process, and so linked the recommendation to this process. Recommendations 1.3.13 and 1.3.14 were adapted from the NICE guideline on home care. It was also supported by evidence from the expert witness on personal assistants about the importance of having a good match between the needs of the person, and the skills and knowledge of their personal assistant or carer. The wording was adapted to make this relevant to all care settings, and to make reference specifically to cultural, religious and communication needs. Recommendation 1.3.15 was adapted from the NICE guideline on dementia (recommendation 1.1.1.3), following consideration of the overlapping guidelines in the scope. This was adapted to focus on recording in care plans, as the other parts of this recommendation had already been covered elsewhere. The view of the Committee was that care and support plans provided an important mechanism for identifying and addressing equality and diversity issues. Evidence statement V6 supports this by reference to the need to respect cultural and personal values when tailoring and delivering care to meet the specific needs of the individual. Recommendation 1.3.15 was based on 1 evidence statement from a single study of views and experience of LGBTQI people's experience of employing personal assistants. The Guideline Committee noted that not being able to talk to their PA or to be supported by their PA to live their life as they wish to express in

	terms of sexuality or gender identity was a significant barrier to positive experiences of care. Recommendations 1.3.16 and 1.3.17 were based on Guideline Committee consensus, following stakeholder consultation that discussed the importance of planning ahead to prevent or delay or reduce the need for services and support should be reviewed regularly to remain responsive and relevant to people's needs.

Topic/section heading	**Assessment and care planning: Personal budgets and direct payments**
New recommendations	1.3.18 The local authority must include the person's personal budget in their care and support plan, in line with the Care Act 2014. 1.3.19 Local authorities should: • inform people that they have the option to control their own funding to buy different sorts of care that meets their needs and chosen outcomes • provide information, advice and support so that the person can choose which option suits them best • give people the opportunity to exercise as much control as possible over the way they use any allocated funds to purchase a care package • inform people of the different payment systems available. 1.3.20 Local authorities should ensure that the direct payment process is: • transparent about how the level of funding is decided • straightforward • accessible to all adults who receive social care and are eligible for local authority funding • reviewed periodically to make sure that it is meeting the objectives of the care and support plan. • able to meet the legal obligations of the person receiving that direct payment if they employ personal assistants. 1.3.21 Local authorities should provide accessible information about direct payments, and peer support for people to use them. For example, this could be provided through user-led Centres for Independent Living. 1.3.22 In line with the Care Act statutory guidance, local authorities should support local services that provide peer support. Their contribution could include: • financial support for local peer support services • providing physical space for people who give peer support to hold meetings with people who use services • helping peer support services with applying for grants for funding.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.

Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services?
Quality of evidence	The evidence for these recommendations was taken from the review of user views about aspects of experience of using adult social care service that are positive or valued. The evidence for recommendation 1.3.19, which is about giving service users control of their funding when purchasing different forms of care, and control over the use of allocated funds to purchase a care package, is based on 4 evidence statements. Evidence statement LDV1 is based on 2 poor quality UK studies. Evidence statement TLAPV1 is based on 5 TLAP videos, all which were rated as low quality and explore the use of personal assistants from an employer's perspective. Evidence statement U6RQ1-3 is based on 1 high, 1 medium and 1 low quality UK study. Evidence statement V4 is based on 9 UK studies, of which 3 are rated high quality and 6 are rated medium quality. The evidence for recommendation 1.3.20, in respect of the direct payment process being transparent, accessible and straightforward is based on 2 high quality studies, 1 medium level study and 1 low quality study, all from the UK. The evidence in relation to accessible information about direct payments and peer support for people who use them (recommendation 1.3.21) is provided by 2 high quality studies, 1 medium level study and 1 low quality study, all from the UK. The evidence in relation to local authorities ensuring that local peer support services are sufficiently resourced (recommendation 1.3.22) is provided by 2 high quality studies, 2 medium level study and 1 low quality study, all from the UK.
Economic considerations	Although no economic evidence was available to inform these guideline recommendations, the Guideline Committee was mindful of potential costs and resource use when making the recommendations. The Guideline Committee considered carefully the potential resource impact of peer support arrangements, including user-led Centres for Independent Living. However, it was the view of the Committee that these types of arrangements were associated with best user experiences. The wording of recommendation 1.3.22 is intended to convey that local authorities can support local peer support in a range of ways that are not solely financial. The Committee also noted that peer support and user-led organisations are also recommended in the statutory guidance in the Care Act 2014, and so are recognised more widely as good practice.
Evidence statements – numbered evidence statements from which the recommendations were developed	LDV1 (recommendation 1.3.19) TLAPV1 (recommendation 1.3.19) U6RQ1-3 (recommendation 1.3.19) V4 (recommendation 1.3.19) V5 (recommendations 1.3.20, 1.3.21, 1.3.22)
Other considerations	Recommendation 1.3.18 was a consensus recommendation, aiming to make clear the statutory responsibilities in relation to personal budgets.

	Recommendation 1.3.19 was based on evidence statements LDV1, TLAPV1, U6RQ1-3 and V4. These highlighted the importance of tailoring services, and the potential value of employing a personal assistant. The Guideline Committee discussed the fact that having control over funding was a key mechanism by which people could ensure that services were tailored to meet their needs, including employing a personal assistant if they wished to. The Committee thought that many people were not aware of their rights in relation to having control over their own funding, which would then preclude them making use of the flexibilities this affords. This recommendation therefore focused on giving people the information they required. The Guideline Committee also noted that provision of information about funding is a requirement of the statutory guidance within the Care Act 2014. Following stakeholder consultation the Guideline Committee added detail that people should be made aware of all payment types available to them, in order that they can choose the methods that would suit them best. In terms of the other recommendations 1.3.20, 1.3.21 and 1.3.22, these were discussed in the context of evidence statement V5, which states that personal budgets and direct payments are too complicated and the application process is very cumbersome. The Guideline Committee discussions reflected these issues and also acknowledged that people are left unsupported to manage their budgets; peer support was suggested as offering one of a number of potential solutions. Stakeholder consultation comments gave examples of how sudden changes to payments could lead a person who employed personal assistants to breach their responsibilities as employers, in terms of redundancy rules and notice periods. To address this, detail was added to this recommendation to say that the payment process should take account of the person's legal obligations as employers. This was also supported by Barnes and Mercer (2006) in evidence statement V5, which found that formal and informal peer support provided by other disabled people active in user-led disability services, was identified as helpful in reducing social isolation. Peer support has been included as part of recommendations 1.3.21 and 1.3.22.

Topic/section heading	**Assessment and care planning: Personal assistants**
New recommendations	1.3.23 If people have eligible needs that could be met by employing a personal assistant, the local authority should ensure that this option is discussed with the person and understood by them at the care and support planning stage. 1.3.24 In line with the Care Act statutory guidance, local authorities should ensure that support is available for people employing personal assistants, and that they are told about where to get support with:

	- recruitment and retention of staff - their role and responsibilities as an employer (for example, payroll, terms and conditions, redundancy and contingency planning). 1.3.25 Local authorities should consider the following to deliver support for people who employ personal assistants: - user-led Centres for Independent Living - other peer-support arrangements. 1.3.26 In line with the market shaping duty in the Care Act 2014, local authorities should work with people who use social care services and their carers to enable access to personal assistants. For example, this could be done by providing training opportunities for people who are interested in becoming personal assistants.
Research recommendations	The Guideline Committee did not prioritise this as an area on which to make research recommendations.
Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services? 2. For people who use adult social care services, what are the barriers related to improving their experience of care? 3. For people who use adult social care services, what would help improve their experience of care?
Quality of evidence	The evidence for these recommendations was taken from the reviews of user views about aspects of experience of using adult social care service that are positive or valued; user views about barriers related to improving their experience of care; and user views about what would help improve their experience of care. Evidence in relation to valuing personal assistants was provided by 1 medium level quality and 5 poor quality UK studies (including 3 videos). The evidence on supporting people with the employment of PAs was provided in video evidence TLAPV3, which was of low quality and based on 3 videos, and on expert witness testimony.
Economic considerations	Although no economic evidence was available to inform these guideline recommendations, the Guideline Committee was mindful of potential costs and resource use when making the recommendations. For recommendation 1.3.25, it was noted that peer support may not be uniformly available across the country, and could therefore entail investment in some areas. The Committee therefore decided to make this a 'consider' recommendation. However, the Committee also noted that peer support is recommended in the statutory guidance in the Care Act 2014. The Guideline Committee also considered the potential resource impact of the recommendation on shaping the market for personal assistants, but noted that market shaping is a statutory duty under the Care Act 2014, and therefore is something that local authorities should already be doing.
Evidence statements – numbered evidence	TLAPV2 (recommendation 1.3.23) TLAPV3 (recommendations 1.3.23 and 1.3.24)

statements from which the recommendations were developed	LD7 (recommendation 1.3.23) V10 (recommendation 1.3.23)
Other considerations	Recommendation 1.3.23 was based on evidence statements TLAPV2, TLAPV3, LD7, V10 expert testimony, and the professional and personal experience of Guideline Committee members, which suggested that many people may not be aware that they can employ personal assistants. The view of the Committee was that this should be discussed with people as part of developing their care plan. Recommendation 1.3.24 was based on evidence statement TLAPV3 and was an issue raised by the expert witness. Whilst support with the human resources aspects of employing personal assistants is a statutory responsibility of the local authority, the view of the expert witness was that this does not always happen in practice. The view of the expert witness and Guideline Committee members was that this support is vital in ensuring that people have a good experience of employing a personal assistant. Stakeholder consultation comments also raised the complexities of employing personal assistants. The Guideline Committee added detail that local authorities should make clear what the responsibilities of employing personal assistants would likely entail and how to access support for people who employ personal assistants. Recommendation 1.3.25 reflected the expert witness testimony and the professional and personal experience of Guideline Committee members that peer support is a useful mechanism for providing support. Recommendation 1.3.26 was based on the expert witness' testimony, which identified an improved market for personal assistants as a key driver for improving people's experiences of services. The Guideline Committee discussed what local authorities can do to make sure that there are a range of skills and abilities of personal assistants, that it is an attractive job opportunity, in order to help people who use personal assistants support the personal assistants' professional development.

Topic/section heading	**Providing care and support - care and support in all settings**
Recommendations	1.4.1 Service providers should foster a culture that enables practitioners to respect people's individual choices and preferences, in all settings where care and support is delivered, by:

	• co-producing policies and protocols with people who use services and their carers (see recommendation 1.1.9) • ensuring that there are open channels of communication between practitioners and people who use services • using the communication methods that suit the person, in line with the Accessible Information Standard • supporting people to take managed risks to achieve their goals – for example, taking part in hobbies or sports • ensuring that there are systems in place for reporting concerns or abuse • ensuring that practitioners have the time to build relationships with people • training and supporting practitioners to work in this way, and checking they are doing so. 1.4.2 Practitioners working in all settings where care and support is delivered should ask the person using services, their carers, family, friends and advocates what name they prefer to be called, and use their preferred name. 1.4.3 Practitioners working in all settings where care and support is delivered should take time to build rapport with the people they support[39]. 1.4.4 Practitioners working in all settings where care and support is delivered should respond flexibly to the priorities a person might identify each day. For example, a person might ask a home care worker to spend more time helping them get dressed and less time on other tasks if they have a special event to attend. 1.4.5 Day care and residential care providers should offer a choice of activities that are led by the person's needs, preferences and interests. Encourage people to take part by including activities that motivate them, support them to learn new skills and increase their level of independence. Recognise that preferences are not fixed and may change.
Research recommendations	What are the views and experiences of people who use adult social care services on assistive technologies?
Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services? 2. For people who use adult social care services, what are the barriers related to improving their experience of care? 3. For people who use adult social care services, what would help improve their experience of care? 4. What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?
Quality of evidence	The evidence that care users lack control (or perceive a lack of control) over decisions made about entering care and/or

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[39] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

	transitions between care is based on 5 UK studies of medium to high quality. The evidence that consistency of care delivery (in terms of what is being delivered and who delivers it) is important to adults in receipt of home care, improves relationships between carers and users and improves the quality of care, is found in 4 UK studies of medium to high quality. There is a small amount of evidence of medium quality that service delivery often lacked the personal touch. This was provided by two 2 UK studies of medium quality. The evidence that engaging care home residents in conversations facilitated good service experience is found in 4 medium quality UK studies. The evidence that resource and time constraints affect the quality of care experienced by residents in care homes is found in 5 UK studies of medium to high quality. The evidence that consistency of care impacts on the quality of care being received is based on 4 UK studies of medium to high quality.
Economic considerations	Although no economic evidence was available to inform these guideline recommendations, the Guideline Committee was mindful of potential costs and resource use when making the recommendations. The view of the Committee was that these recommendations related largely to undertaking existing activities in a slightly different way, and so should not have a significant resource impact. In relation to 1.4.5, the Committee recognised that offering choice may have some resource impact, but that the choice of activities did not necessarily need to be high cost.
Evidence statements – numbered evidence statements from which the recommendations were developed	BF1 (recommendation 1.4.2) BF3 (recommendation 1.4.1) BF4 (recommendation 1.4.3) RCB2 (recommendation 1.4.4) V2 (recommendation 1.4.2) LD6 (recommendations 1.4.5)
Other considerations	Recommendation 1.4.1 was based on BF3, which found that services often lacked 'the personal touch'. The Guideline Committee discussed the nature of building relationships in residential care homes; some relationships are professional, some are therapeutic. The Committee discussed that the issue of care lacking a personal touch may be more acute in a residential care home setting, but the evidence that people value personalised care would be relevant to people who receive care in all settings. Recommendation 1.4.2 was adapted from the NICE guideline on service user experience in adult mental health (recommendation 1.1.3), which was identified as being of particular relevance to this guideline. It was supported by evidence from our review which found that people who use services feel that they lack control over decisions made about entering care and/or transitions between care settings, which can affect how well they

	settle into their new environment. The Guideline Committee noted that this went further than just about forms of communication or communication style, but about defining active participation and developing a genuinely collaborative approach. Recommendation 1.4.3 was based on BF4, which found that engaging care home residents in conversations facilitated good service experience. The Guideline Committee made the recommendation based on the evidence that engaging people in genuine interaction with people is important for their sense of self-worth and value. The Guideline Committee agreed to extrapolate this evidence to all care settings. Recommendation 1.4.4 was based on evidence that resource and time constraints impacted on good care in residential care homes (RCB2). The Guideline Committee discussed that using time more flexibly may be helpful. Working within time and resource constraints, staff should focus on understanding what people actually want and ask people what their priority for the day would be. The Committee thought it was appropriate to extrapolate this evidence to apply to all care settings. Recommendation 1.4.5 was based on evidence statement LD6, which suggested that people with learning disabilities have little say or control over their lives in residential care. The Guideline Committee extrapolated from this to cover all user groups, based on their professional experience and practice in the importance of offering meaningful choice to facilitate some control over aspects of one’s life. The evidence was also extended so that the recommendation also covers day care services, as the issue of offering a range of activities was also thought to be relevant in this setting. Stakeholder consultation comments suggested that people should be actively encouraged to take part in activities that stimulated them so that people were not side-lined or 'difficult' people ignored. This information was added, based on Guideline Committee consensus.

Topic/section heading	**Providing care and support – continuity and consistency**
Recommendations	1.4.6 Service providers in all settings, with oversight by commissioners, should review staffing numbers and skill mix regularly to ensure that staffing and skill levels are sufficient. 1.4.7 Commissioners and managers in all settings should ensure that there is continuity in care and support for people, including:

	• ensuring that all practitioners involved with the person's care and support are familiar with how that person likes support to be given • where possible, the same people are supporting the person • if the same staff are not available, ensuring there are good handover arrangements • ensuring that all staff supporting the person have similar levels of skills and competency • using the same independent advocate where possible. 1.4.8 Providers and managers in all settings should ensure that: • people are informed in advance if staff will be changed and • any changes to care and support – for example, when visits will be made, are negotiated with the person. 1.4.9 Support people to make decisions about entering a new care setting or moving to a different setting. For guidance on transitions between particular settings, see the NICE guidelines on: • transition from children's to adults' services for young people using health or social care services • transition between inpatient hospital settings and community or care home settings for adults with social care needs • transition between inpatient mental health settings and community or care home settings. 1.4.10 To support collaborative working between services, commissioners and managers should consider putting the following in place: • a local policy for sharing information relevant to people's care within and between services in line with the Caldicott principles and the Health and Social Care (Safety and Quality) Act 2015 • joined-up policies, processes and systems.
Research recommendations	What are the views and experiences of people who use adult social care services on assistive technologies?
Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services? 2. For people who use adult social care services, what are the barriers related to improving their experience of care? 3. For people who use adult social care services, what would help improve their experience of care? 4. What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?
Quality of evidence	The evidence that day care and residential care providers should offer a choice of activities that are led by the person's needs, preferences and interests is based on 1 UK study rated medium quality.

	The evidence for the recommendation about commissioners and service providers in all settings needing to review staffing numbers and skill mix regularly to ensure that staffing and skill levels are sufficient comes from 5 UK studies: 1 rated high quality, 3 rated medium quality; and 1 rated low quality. The evidence for recommendation 1.4.7 that commissioners and service managers in all settings should ensure that there is continuity in the care and support for people comes from evidence statement V2 containing 4 UK studies, of which 1 was rated high quality and 3 were rated medium quality. The evidence for recommendation 1.4.8 is based on the same evidence statement above consisting of 4 studies, of which 1 was rated high quality and 3 studies were of medium quality. The evidence about supporting people to make decisions about entering a care setting (recommendation 1.4.9) was provided in 9 studies across 2 evidence statements. Four studies were of high quality and 5 studies of medium level quality, all of which were from the UK. The evidence for recommendation 1.4.10 came from 1 evidence statement consisting of 1 high quality and 2 medium quality UK studies.
Economic considerations	Although no economic evidence was available to inform these guideline recommendations, the Guideline Committee was mindful of potential costs and resource use when making the recommendations For recommendations 1.4.7 and 1.4.8 the Committee considered carefully the feasibility and resource impact of these recommendations, recognising that having the same individuals supporting a person is not always possible – hence the need for good handover and consistent skills across teams.
Evidence statements – numbered evidence statements from which the recommendations were developed	RCB2 (recommendation 1.4.6) V2 (recommendation 1.4.7, 1.4.8) V2 (recommendation 1.4.9) BF1 (recommendation 1.4.9) V8 (recommendation 1.4.10)
Other considerations	Recommendation 1.4.6 was based on evidence statement RCB2, which found resource and time constraints affect the quality of care experienced by residents in care homes. The Committee considered it appropriate to extrapolate this to other care settings. The Committee recognised that correct levels of staffing and skills will differ between services, so emphasised the importance of review, rather than specifying particular staffing or skill levels. Recommendations 1.4.7 and 1.4.8 were based on evidence statement V2, that people appreciate consistency in aspects of their care. The Committee acknowledged that practicalities of providing care meant that it was not always possible for the same individuals to deliver a person's care. The recommendation therefore focuses on ensuring that there is good handover between staff members, and that levels of skill and knowledge

	across the staff team are consistent. The Guideline Committee also noted that consistency did not mean rigidity of care offered and that people's needs and preferences may change over time. The evidence related to people who were receiving care at home. The Guideline Committee agreed that this experience was relevant to other settings. The Guideline Committee also considered whether assistive technology could deliver consistency of care, including a small amount of evidence on call alarms (RCB8), but there was not enough robust research evidence to support a recommendation. The Committee agreed that this would be an area for future research. Recommendation 1.4.9 was based on evidence statements BF1 and V2 and Guideline Committee consensus about the importance of supporting people to make decisions in relation to transitions. The evidence statement was based on research conducted in residential care, but the Guideline Committee thought it was appropriate to extrapolate this to other kinds of care. The existing NICE guidelines on: • transition from children's to adults' services for young people using health or social care services, • transition between inpatient hospital settings and community or care home settings for adults with social care needs and • transition between inpatient mental health settings and community or care home setting were reviewed, and were considered to be relevant to this population. Recommendation 1.4.10 was based on evidence statement V8. The Guideline Committee discussed the organisational arrangements that needed to be in place to support individual practitioners to work across service boundaries. These included consistent policies and processes, and joint commissioning. Additional detail on the relevance of the Health and Social Care (Safety and Quality) Act 2015 to this recommendation was based on Guideline Committee consensus following stakeholder consultation.

Topic/section heading	**Providing care and support – personal and residential care**
Recommendations	1.4.11 All practitioners providing personal care should ensure that personal care needs are responded to in a timely, appropriate and dignified manner in line with the person's wishes and their support plan – for example, making sure that people can go to the toilet when and how they want. 1.4.12 Service managers and practitioners in day care and residential settings should promote a sense of community and mutual support – for example, by facilitating interactions and building social connections between residents through activities such as social events.

	1.4.13 Practitioners and managers in residential settings should: • ensure that the environment allows for people's preferences, self-expression and choice – for example, enabling people to have their own furniture and pictures • support people to have control over their own medicines where possible (see the NICE guideline on managing medicines in care homes) • deliver care and support in a personalised and friendly way • give people privacy, especially when delivering personal care • treat people with dignity and respect. 1.4.14 When designing residential services, providers should ensure that environments: • create space where practitioners and residents can have positive interactions • are welcoming to visits from family, friends, carers and advocates • are stimulating, while not creating additional challenges for residents, including those with sensory impairments or dementia (for example, if the layout is frequently changed or there is poor lighting) • enable positive risk taking (for example, being able to use outside spaces) • support residents' autonomy (for example, by adapting kitchen facilities for people with physical disability).
Research recommendations	What are the views and experiences of people who use adult social care services on assistive technologies?
Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services? 2. For people who use adult social care services, what are the barriers related to improving their experience of care? 3. For people who use adult social care services, what would help improve their experience of care? 4. What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?
Quality of evidence	The evidence for the recommendation that staff providing personal care should ensure that these needs are responded to in a timely, appropriate and dignified manner in line with the person's wishes and their support plan is provided by 2 UK studies, 1 rated high and 1 rated medium quality. The evidence that service managers and staff in day care and residential settings should promote a sense of community and mutual support is found in evidence statement BF5, which consists of 3 UK studies, 1 rated high, 1 rated medium and 1 rated low. Evidence about practitioners and managers in residential settings ensuring that the environment allows for people's preferences,

	self-expression and choice is based on 2 evidence statements. Together these consist of 1 high quality study, 2 medium quality studies and 1 study rated low quality, all of which are from the UK. The evidence about providers ensuring that residential services are designed so that they should be stimulating environments, that allow positive risk taking and are conducive to positive interactions between staff and residents comes from 8 UK studies, 1 rated high quality, 6 rated medium and 1 rated low quality.
Economic considerations	Although no economic evidence was available to inform these guideline recommendations, the Guideline Committee was mindful of potential costs and resource use when making the recommendations.
Evidence statements – numbered evidence statements from which the recommendations were developed	BF4 (recommendation 1.4.14) BF5 (recommendation 1.4.12) RCB1 (recommendation 1.4.13) RCB3 (recommendation 1.4.13) RCB6 (recommendations 1.4.11) RCB9 (recommendation 1.4.14)
Other considerations	Recommendation 1.4.11 was based on evidence that residents of care homes experience long waiting times for delivery of personal care (RCB6). Reference to dignity and respecting people's wishes was based on the professional and personal experience of Guideline Committee members. Recommendation 1.4.12 was based on evidence that community or peer support can facilitate positive adult wellbeing (BF5). The Guideline Committee noted that this was also indicated by recommendation 1.4.16 from the NICE guideline on older people with multiple long term conditions. The recommendation focuses on residential care and day care as 2 settings in which care is communal. Recommendation 1.4.13 was based on evidence that residents of care homes experience a lack of dignity in care received, and that care home residents can experience abusive practice (RCB1, RCB3). Examples of how to ensure that care homes can support people's dignity were provided from the professional and personal experience of Guideline Committee members. Following stakeholder consultation comments, the Guideline Committee added a further example of how people can exert choice and control in a residential care home environment by managing their own medicines wherever possible. A link was provided to the NICE guideline on managing medicines in care homes. Recommendation 1.4.14 was based on evidence that the layout and/or design of care homes is a barrier to service use, inhibiting communication among residents (especially those with sensory impairments) and a lack of freedom for residents, and conversely that there was evidence that engaging care home residents in conversations facilitated good service experience (RCB9, BF4). The Guideline Committee considered the need to encourage

	managers to have a more open attitude to risk, so that people are given more freedom and are not institutionalised. The Committee talked about how these are ‘philosophies of care rather than practical considerations’. The Guideline Committee also noted that engaging people in conversation about more than their care is important for their sense of self-worth and value. The Guideline Committee added further detail to this recommendation following stakeholder consultation comments that a poorly designed residential environment in terms of changing layouts, and poor lighting can pose additional challenges to people with sensory impairments or people who are sensitive to over-stimulation. In addition, the Guideline Committee added detail to this recommendation that environments should be welcoming to friends and family if they are to maintain family and social connections.

Topic/section heading	**Providing care and support – residential care and end of life support**
Recommendations	1.4.15 Ensure that support in residential care is based on a good understanding of people's needs, including: • providing practical and emotional support • accommodating speech and communication needs • helping people to maintain the personal relationships and friendships that are important to them • supporting people to take part in activities and social groups that they want to be involved in, both in the residential setting and in the community • viewing behaviour that challenges as communication • providing access to community health teams and specialist support. 1.4.16 Practitioners should support people to participate fully in tasks and activities by ensuring that: • the environment is conducive to their needs • they have access to the equipment they need (for example, hoists or recliner chairs). 1.4.17 Managers should ensure that practitioners are trained to support residents to use any equipment they need. 1.4.18 Managers in residential settings should co-produce a policy on end-of-life care with people who use services and their carers. This should include information about: • documenting treatment and care preferences at the earliest opportunity (including formal ways of documenting preferences such as Lasting Power of Attorney for health

	and care decisions or advance statements of wishes and care preferences) - a named lead in the residential setting - training on supporting people and their carers at the end of their lives, tailored to different staff groups and updated regularly - ongoing support to enable practitioners to support people near the end of their lives, including creative ways of engaging people in discussions (for example, opportunities to discuss end of life care with peers). 1.4.19 Managers in residential settings should consider making someone available who is independent and not part of the usual staff team to discuss end of life issues, for people who want to do this – for example, from an advocacy organisation.
Research recommendations	What are the views and experiences of people who use adult social care services on assistive technologies?
Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services? 2. For people who use adult social care services, what are the barriers related to improving their experience of care? 3. For people who use adult social care services, what would help improve their experience of care? 4. What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?
Quality of evidence	The evidence for recommendation 1.4.15, which includes the need to ensure that support is provided to people and includes emotional and practical support, speech and communication support, and activities, is provided by 4 studies from the UK; 1 rated high quality, 2 rated medium and 1 rated low. The evidence for recommendation 1.4.15 that staff should support people to participate fully in tasks and activities comes from 6 UK studies, 1 rated high quality and 5 rated medium. The evidence for the recommendation 1.4.16 that managers should ensure that staff are trained to support residents to use any equipment they need comes from 6 UK studies, 1 rated high quality and 5 rated medium. The evidence that managers in residential settings should co-produce with people who use services a policy on end of life care is based on 3 UK studies, 2 rated medium and 1 rated high. Similarly, the evidence that in residential care settings, managers should consider making available someone who is independent and not part of the usual staff team to discuss end of life issues for people who want to do this is based on 3 UK studies, 2 rated medium and 1 rated high.
Economic considerations	Although no economic evidence was available to inform these guideline recommendations, the Guideline Committee was mindful of potential costs and resource use when making the recommendations. In relation to 1.4.16 the Guideline Committee considered the resource implications of access to equipment. However, the research evidence reviewed suggested that the

	difficulty was more related to staff awareness and ability to use equipment, rather than there being a lack of equipment in the setting.
Evidence statements – numbered evidence statements from which the recommendations were developed	BF6 (recommendation 1.4.16, 1.4.17) BF7 (recommendation 1.4.16, 1.4.17) RCB1 (recommendation 1.4.15) RCB3 (recommendation 1.4.15) RCB4 (recommendation 1.4.18, 1.4.19)
Other considerations	Recommendation 1.4.15 was based on RCB1 and RCB3, which found that residents of care homes experience a lack of dignity in care received and evidence that care home residents can experience abusive practice. The Guideline Committee aimed to emphasise the importance of care homes providing people a 'home from home'. The approach to supporting people should therefore not be 'institutional' or punitive, but rather to treat residents like a paying guest. Recommendations 1.4.16 and 1.4.17 was based on evidence statements BF6 and BF7, that giving care home residents a role to play, or an activity to be involved in, mitigated 'loss of identity'. There was also evidence that key professionals lack adequate knowledge and training to support this. The Committee discussed the difference between environment and equipment. Although these can sometimes be inter-linked, as equipment can act as an enabler (e.g. time, extra space, quiet room can be seen as 'equipment') staff should be trained and supported to use this equipment. Recommendations 1.4.18 and 1.4.19 were based on evidence statement RCB4, that people experienced a lack of clarity over who should be the lead professional in end-of-life care discussions. The Guideline Committee considered the importance of training and support for a wide range of staff to make sure appropriate end-of-life conversations and provisions can happen.

Topic/section heading	**Staff skills and experience**
Ne recs	1.5.1 Have a transparent and fair recruitment and selection process that: • uses values-based interviews and approaches to identify the personal attributes and attitudes essential for a caring and compassionate workforce and • ensures that staff have the necessary language, literacy and numeracy skills to do the job[40]. 1.5.2 Local authorities should ensure that people undertaking needs and eligibility assessments have the knowledge and skills

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[40] This recommendation is adapted from the NICE guideline on home care.

	to carry out assessments as described in recommendations 1.3.3 to 1.3.9. 1.5.3 Service providers should consider involving people who use services and their carers ('experts by experience') in the recruitment and training of staff. For example: • being on interview panels • contributing to development and delivery training • helping to develop job descriptions • supporting and training others to be experts by experience. 1.5.4 Consider providing opportunities for practitioners to learn from the personal experiences of all people who use services, in all settings where care and support is provided. This could be through: • forums within residential and day care services • audit, planning and evaluation of services • practitioners being mentored by people who use services. 1.5.5 Service providers should ensure that practitioners are aware of the local arrangements for, and understand the function of, other services that they may need to work with, such as other health and social care service providers and services provided by the voluntary sector.
Research recommendations	What are the views and experiences of people who use adult social care services on assistive technologies?
Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services? 2. For people who use adult social care services, what are the barriers related to improving their experience of care? 3. For people who use adult social care services, what would help improve their experience of care?
Quality of evidence	Evidence for the recommendation that education providers should ensure that training for people undertaking social care assessments that enables them to meet the standards for assessment, is based on 2 UK studies, 1 rated high and 1 rated medium. Evidence for the recommendation that service providers should involve people who use services ('experts by experience') in the recruitment and training of staff is based on 1 UK study rated high quality. The recommendation that staff should have opportunities to learn from the personal experiences of people who use services is based on 2 UK studies, 1 rated high and 1 rated medium. The recommendation that service providers should ensure that staff are aware, and understand the function, of other services that they may need to work with also comes from 2 UK studies, 1 rated high and 1 rated medium.
Economic considerations	Although no economic evidence was available to inform these guideline recommendations, the Guideline Committee was mindful of potential costs and resource use when making the recommendations. For recommendation 1.5.3, the Guideline

	Committee considered the resource implications of involving people in recruitment and training but were of the view that this was relatively common practice, and so was an aspirational but achievable recommendation.
Evidence statements – numbered evidence statements from which the recommendations were developed	BF7 (recommendation 1.5.4, 1.5.5) RCB7 (recommendation 1.5.3)
Other considerations	Recommendation 1.5.1 was adopted from the NICE guideline on home care (recommendation 1.7.1). This was considered to be relevant because users of home care services are one of the groups covered by this guideline. Values-based recruitment of staff was felt to be relevant to improving experience of all adult social care users. Recommendation 1.5.2 was developed by committee consensus and reflected the fact that, given the importance of assessment in understanding people's needs, the people undertaking assessment needed the rights skills and experience to be able to do this. Recommendation 1.5.3 was based on evidence about staff in care homes who felt undervalued, which could affect the quality of care provided. The Committee discussed a range of issues related to the provision of high quality support for people in care homes, and what this means for recruitment, training and support of staff. The Guideline Committee thought it was appropriate to extrapolate this evidence to make a recommendation about all care settings. Reference to involving people who use services in recruitment and training was based on the professional and personal experience of Guideline Committee members. Recommendation 1.5.4 and 1.5.5 comes from evidence about a lack of knowledge and training for professionals in some areas, including ‘blockages’ to connecting social care and primary care services. The Committee made a recommendation on improving the knowledge and skills of staff to overcome these blockages, and also discussed how people using services can influence and improve the way staff are trained. Reference to the voluntary sector was added by the Guideline Committee following stakeholder feedback.

Topic/section heading	**Staff skills and experience**
New recommendations	1.5.6 Service providers should provide opportunities for practitioners to take part in interprofessional learning and development.

	1.5.7 Service providers should ensure that practitioners are able to use any equipment or devices people need – for example, hearing aid loops. 1.5.8 Service providers should ensure that practitioners are aware of issues relating to information sharing and confidentiality.
Research recommendations	What are the views and experiences of people who use adult social care services on assistive technologies?
Review questions	1. Which aspects of the experience of using adult social care services are positive or valued by people who use services? 2. For people who use adult social care services, what are the barriers related to improving their experience of care? 3. For people who use adult social care services, what would help improve their experience of care?
Quality of evidence	The recommendation that service providers should provide interprofessional learning and development opportunities for staff is based on 2 UK studies, 1 rated high and 1 rated medium. There were 2 UK studies, 1 rated high and one rated medium quality, that professionals lacked the necessary knowledge and skills linking social care and primary care and the ability to use equipment and aids effectively.
Economic considerations	Although no economic evidence was available to inform these guideline recommendations, the Guideline Committee was mindful of potential costs and resource use when making the recommendations.
Evidence statements – numbered evidence statements from which the recommendations were developed	BF7 (recommendation 1.5.6, 1.5.7)
Other considerations	Recommendation 1.5.6 was based on evidence about a lack of knowledge and training for professionals in some areas, including ‘blockages’ to connecting social care and primary care services (BF7). The Committee made a recommendation on improving the knowledge and skills of staff to overcome these blockages, and also discussed how people using services can influence and improve the way staff are trained. The Guideline Committee expanded the recommendation to include this. Recommendation 1.5.7 was based on evidence about a lack of staff skill in using equipment that people need within a care home environment (BF7). This has equality implications, particularly in relation to people with sensory or mobility impairments. The Guideline Committee thought that this evidence could be extrapolated to apply across care settings. Recommendation 1.5.8 was a consensus recommendation, based on the professional and personal experience of Guideline Committee members. Guideline committee discussions highlighted the importance of balancing the involvement of family

	and friends with maintaining the person's confidentiality and dignity.

Topic/section heading	**Involving people in service design and improvement**
Recommendations	1.6.1 Local authorities must provide opportunities for people who use services to be involved if they want to in strategic decision-making about services, not just their own care and support, in line with the Local Government and Public Involvement in Health Act 2007. This should include involving people in: • decisions about the way services are commissioned, run and are governed and • checking that the service is delivering quality care and support. 1.6.2 All research into the views of people using care and support and their carers should be co-produced at all stages, including the research design, how it is carried out, and any resulting actions (for example, developing or refining quality indicators, developing monitoring tools or identifying gaps in services). 1.6.3 Commissioners and service providers should communicate clearly the outcome that any exercise to collect people's views is aiming to achieve and what will be done as a result. 1.6.4 Commissioners and service providers should consider using a range of approaches to gather views and experiences (for example, focus groups, interviews or observation in addition to surveys), and use evidence from a range of sources. This could include: • the lived experiences of people who use services • information from third sector and voluntary organisations that represent people who use social care services – for example, Healthwatch • existing sources of information, such as complaints. 1.6.5 Local authorities should consider gathering and analysing evidence on people's experience of services in collaboration with other health and social care organisations serving the same populations to reduce duplication and ensure economies of scale. 1.6.6 Organisations conducting research should consider from the outset how to ensure that all groups are able to participate, including people who may lack capacity and people with different communication needs. This may involve adapting different research methods (see recommendation 1.6.4) or providing materials in a range of formats. If the participation or response rate for a particular group is low, the organisations should take action to improve it. This could include investigating what specific communication or cultural reasons may account for the low response and adapting materials or response formats to better suit that group.

Research recommendations	When conducting research for the purposes of service improvement, what research methods are acceptable, appropriate and effective in meaningfully gathering the views and experiences of people who use services? What approaches have been shown to work in supporting the co-production of research for the purposes of service improvement with people who use services? What are the barriers and enablers to gathering, synthesising and applying data on the views and experiences of service users for the purposes of service improvement?
Review questions	4. What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?
Quality of evidence	The evidence on people's involvement in decision-making is provided by 1 medium quality qualitative study. The setting for the study was in a care home, but the findings were extrapolated to other settings. The evidence on methods used to collect people's views and experiences to improve services was provided by 4 studies, 3 of medium quality and 1 of low quality. The evidence that current tools for measuring levels of satisfaction require some modifications and further testing was provided in 3 medium quality UK studies. The evidence that people who may lack capacity can be supported in participating in decisions came from 1 medium quality study. The evidence that current tools for measuring levels of satisfaction require some modification and testing came from 2 medium quality studies and 1 high quality study.
Economic considerations	The Committee sought evidence relating to cost-effectiveness of different approaches to gathering information. No research evidence was available, so an expert witness was invited. The expert witness confirmed that there is no conclusive cost-effectiveness evidence relating to which methods are more cost-effective, either in securing people's participation, or in leading to improvements to services and people's outcomes. The expert witness further advised that a single approach to data gathering was unlikely to be suitable for all social care users, and that a variety of approaches would be required to enable wide participation. The Guideline Committee considered the resource implications of the recommendations. It was the view of the Committee that a number of the recommendations represented slightly different ways of undertaking current activities (for example, how the purpose of any data gathering is communicated) rather than new activities, so a substantial change in resource usage is not anticipated. Some recommendations are aligned with changes to activities mandated elsewhere. For example, the Guideline Committee noted that meaningful engagement with people who use services in developing local commissioning strategies forms part of the statutory guidance on the Care Act 2014.

Evidence statements – numbered evidence statements from which the recommendations were developed	BF2 (recommendation 1.6.1) RQ4.1 (recommendations 1.6.2, 1.6.3) RQ4.2 (recommendation 1.6.2) RQ4.6 (recommendation 1.6.6) U1Q4 (recommendation 1.6.5)
Other considerations	Recommendation 1.6.1 was based on evidence statement BF2 and supported by the professional and personal experience of Guideline Committee members. BF2 found that people's sense of choice and control in care homes could be enhanced by sharing information and being involved in decision-making. The Guideline Committee noted the importance of co-production and user involvement in shaping all services, and so extrapolated this evidence more widely. It was also noted that there is a legal duty under the Local Government and Public Involvement in Health Act 2007 to involve people in decision-making. Meaningful engagement with people who use services in developing local commissioning strategies forms part of the statutory guidance in the Care Act 2014. Recommendation 1.6.2 was based on RQ4.1 and RQ4.2, which related to adapting methods for data gathering to people's preferences and ability to participate, and involving people who use services in translating survey findings. The Guideline Committee noted that co-producing research with people who use services was a good mechanism for ensuring that data collection methods were appropriate, and that any resulting actions would result in improved actions. The committee considered the additional resources that could potentially be required to implement a co-production approach. However, this approach was thought to be in line with best practice in the sector, and as required in the Care Act 2014. Reference to identifying gaps in services, and to involving carers in research, was added by committee consensus based on stakeholder feedback. Recommendation 1.6.3 was based on RQ4.1. The Guideline Committee thought that an important aspect of people being able to participate fully related to having a good understanding of the purpose of the research being conducted and what might happen as a result. It was the view of the Committee that there was some loss of confidence in exercises to gather people's views, and that this could be addressed by having more clarity about why views were being sought. This was not thought to have any associated resource implications. Recommendation 1.6.4 was based on expert witness testimony, which suggested that a range of methods was required to gather views representative of all groups of service users. It was acknowledged that survey research is the most commonly used method, but that this may have limitations in terms of the richness of data gathered, and its accessibility. The Guideline Committee considered the resource implications of recommending other ways of gathering information. However, it was noted that meaningful engagement with people is aligned with statutory guidance on the Care Act 2014. Gathering lived experiences from

	service users, information from voluntary organisations, and using complaints data, were consensus decisions based on the professional experience of the Guideline Committee. Reference to Healthwatch was added based on committee consensus following stakeholder feedback. Recommendation 1.6.5 was based on U1Q4 which found that methods for gathering data needed further development. The Guideline Committee added reference to sharing data collection with other local agencies based on their professional experience. The view of the Committee was that this could potentially lead to cost savings through economies of scale. Recommendation 1.6.6 was based on RQ4.6 and expert witness testimony about the considerations for how to secure adequate response rates to surveys from across service users. The expert witness testimony highlighted that there was no 'one size fits all' approach to achieving response rates, and that a variety of characteristics needed to be taken in to account, which will vary according to the population being involved. The Committee therefore decided to emphasise the role of in thinking through these issues for themselves. The Committee were keen that particular groups should not simply be considered 'hard to reach' – for example people for whom English is not their first language – and that additional steps should be taken to facilitate the participation of these groups. The Committee considered the potential resource implications of this. The Committee's view was that there were some relatively low cost actions which could help participation (for example, working with relevant voluntary organisations). The Committee also noted the imperatives within the Care Act 2014 for meaningful engagement with people who use services. RQ4.6 highlighted that people who may lack capacity can be supported to make decisions. The view of the Committee was that the views of people who may lack decision-making capacity should also be sought. The Guideline Committee added further detail to this recommendation following stakeholder consultation that reasons for low response should be investigated and research tools adapted to ensure that all people can participate.

Topic/section heading	**Gathering information from people who use services**
Recommendations	1.6.7 Service providers should seek the views of people who use services about the extent to which the things that are important to them are being addressed. This should be done in such a way that the person feels safe to express their views, even if these are critical (for example, a care home resident may not want to give feedback directly to the manager). 1.6.8 Organisations or individuals conducting research or seeking feedback from people who use services should ensure that independent advocacy is available and offered when:

	• this would help someone to take part or • the person expresses a preference to use advocacy. 1.6.9 Service providers should consider employing people who use services to monitor people's experience of health and social care services, including conducting research. This could be done by: • offering training to 'experts by experience' on how to conduct interviews with people who use services, including supporting them in applying ethical principles such as informed consent and confidentiality • paying them to undertake exit interviews with people who have recently left a service or moved to another service[41]. 1.6.10 Commissioners and providers should ensure that the results of research with people are used to inform improvements to services. 1.6.11 Commissioners and service providers should make available the results of research with people who use services, using approaches developed with people who use services. This should include: • publishing the results • giving feedback directly to people who took part • making public how they have responded to people's feedback – for example, by using 'you said, we did' tables or case studies.
Research recommendations	When conducting research for the purposes of service improvement, what research methods are acceptable, appropriate and effective in meaningfully gathering the views and experiences of people who use services? What approaches have been shown to work in supporting the co-production of research for the purposes of service improvement with people who use services? What are the barriers and enablers to gathering, synthesising and applying data on the views and experiences of service users for the purposes of service improvement?
Review questions	4. What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?
Quality of evidence	There was a small amount of evidence of medium quality that service delivery often lacked the personal touch. This was provided by 2 studies of medium quality. The evidence on methods used to collect people's views and experiences to improve services was provided by 4 studies, 3 of medium quality and 1 of low quality. The evidence that people who may lack capacity can be supported in participating in decisions came from 1 medium quality study.

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[41] This recommendation is adapted from the NICE guideline on service user experience in adult mental health.

	The evidence that feeding back results of satisfaction surveys to social care management can lead to positive improvements in practice came from 1 medium quality study.
Economic considerations	The Committee sought evidence relating to cost-effectiveness of different approaches to gathering information. No research evidence was available, so an expert witness was invited. The expert witness confirmed that there is no conclusive cost-effectiveness evidence relating to which methods are more cost-effective either in securing people's participation, or in leading to improvements to services and people's outcomes. The expert witness further advised that a single approach to data gathering was unlikely to be suitable for all social care users, and that a variety of approaches would be required to enable wide participation. The Guideline Committee considered the resource implications of the recommendations. In some cases, these were also balanced against the potential equality implications (for example, not providing advocacy is likely to exclude particular groups of people).
Evidence statements – numbered evidence statements from which the recommendations were developed	BF3 (recommendation 1.6.7) RQ4.1 (recommendation 1.6.11) RQ4.6 (recommendation 1.6.8) U2Q4 (recommendation 1.6.10, 1.6.11)
Other considerations	Recommendation 1.6.7 was based on BF3, which related to having a 'personal approach' to providing services. The view of the Committee was that this principle could also be applied to gathering views about services – namely that people need to be given opportunities to feed back on the aspects of care that matter to them, not just taking a 'one size fits all' approach. The Committee also discussed the importance of ensuring that people did not feel that their responses to any research would affect the care they received. Recommendation 1.6.8 was based on RQ4.6 about supporting people to make decisions. The Guideline Committee considered some of the difficulties in gaining someone's informed consent to take part in surveys, but the Guideline Committee noted that if people can be supported to make their own decisions around their healthcare, an advocate may be able to support a person in expressing their views and experiences. The Committee considered the resource implications of offering advocacy, and acknowledged that this would be likely to represent an additional resource. However, this was balanced against the potential for particular groups, particular people with learning disabilities or who may lack capacity, to be excluded from giving their views and experiences in the absence of support. Recommendation 1.6.9 was adapted from the NICE Guideline on service user experience in adult mental health (recommendation 1.1.21), and reworded to be relevant to all people who use social care services. Reference to applying ethical principles was based

	on the Guideline Committee's professional and personal experience, noting that research conducted by people who use services should be enabled to meet high methodological and ethical standards. The Committee considered the resource impact of this recommendation, but were of the view that this was not require significant additional resource, but would instead entail a different use of the resources that would in any case be required to conduct research. Recommendation 1.6.10 was based on U2Q4 and Guideline Committee consensus. The Committee thought it was important to highlight that, wherever possible, the findings of any exercises to gather data should be used to inform improvements to practice. Recommendation 1.6.11 was based on RQ4.1 and U2Q4. It also drew on the Committee's experience that participating in research where the results are not communicated can lead to a lack of trust in the process. The Committee considered the resource implications of the recommendations, but thought that there were some relatively low cost ways to achieve this, such as making the findings available on the local authority website.

Topic/section heading	**Survey research**
Recommendations	1.6.12 Consider using existing validated surveys before deciding to develop a new survey. 1.6.13 Local authorities should analyse the characteristics of people who did not or could not respond to surveys and: • report on any under-represented groups in their published report of the survey and seek to understand the reasons for this • develop ways to address these gaps in the future – for example, by considering alternative modes of response, such as a telephone response line • ensure that information about under-represented groups is fed back to the survey designers. 1.6.14 Local authorities should ensure that people in their organisations who are responsible for interpreting and implementing survey findings have the necessary skills and capacity.
Research recommendations	When conducting research for the purposes of service improvement, what research methods are acceptable, appropriate and effective in meaningfully gathering the views and experiences of people who use services? What approaches have been shown to work in supporting the co-production of research for the purposes of service improvement with people who use services? What are the barriers and enablers to gathering, synthesising and applying data on the views and experiences of service users for the purposes of service improvement?

Review questions	4. What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?
Quality of evidence	The evidence that current tools for measuring levels of satisfaction require some modifications and further testing was provided in 3 medium quality UK studies.
Economic considerations	The Committee sought evidence relating to cost-effectiveness of different approaches to gathering information. No research evidence was available, so an expert witness was invited. The expert witness confirmed that there is no conclusive cost-effectiveness evidence relating to which methods are more cost-effective either in securing people's participation, or in leading to improvements to services and people's outcomes. The expert witness further advised that a single approach to data gathering was unlikely to be suitable for all social care users, and that a variety of approaches would be required to enable wide participation. In the absence of cost-effectiveness evidence, the Committee aimed to consider the resource implications of the recommendations. This is reported in the 'other considerations' section below.
Evidence statements – numbered evidence statements from which the recommendations were developed	RQ4.2 (recommendation 1.6.12)
Other considerations	Recommendation 1.6.12 was based on RQ4.2 and Guideline Committee consensus. The Committee reflected that there are a number of standardised tools for gathering views and experiences available, and that it can be a poor use of resources for local areas to develop new tools unnecessarily. It was the view of the Committee that this recommendation therefore had the potential for cost savings. The Committee's professional and personal experience was that, when individual authorities or providers develop their own tools, these are of variable quality, and are often not appropriately tested and validated. The evidence statement suggested that it is important to ascertain the validity of tools before they are used. Recommendation 1.6.13 was based on was based on expert witness testimony and Guideline Committee consensus. The Guideline Committee were concerned that surveys should not be treated as representative if they are missing the voices of particular groups of people. The Committee considered the resource implications of the recommendation, particularly in relation to providing alternative methods for responding, and decided to make a weaker 'consider' recommendation for this aspect. Recommendation 1.6.14 was a consensus recommendation, based on the Committee's experience that particular skills are required to make use of the results of research. The Committee

	considered the resource implications of this recommendation and thought that the recommendation did not entail new roles or staff, but ensuring that existing staff had the required skills and knowledge.

4 Implementation: getting started

[This section will be finalised after consultation]

NICE has produced tools and resources [link to tools and resources tab] to help you put this guideline into practice.

Some issues were highlighted that might need specific thought when implementing the recommendations. These were raised during the development of this guideline. They are:

- Supporting people who use services to maintain their independence is a key requirement for wellbeing and is an achievable expectation, but it will require a significant change in practice for some services.
- Working with social care users to ensure that there is a well-developed ‘market’ for Personal Assistants (PAs) will lead to better outcomes for people who employ PAs and better use of resources, but for some authorities this will involve a new focus on market development and a change of practice that will require staff re-training.
- Making sure that people are supported in a residential setting that is appropriate to their needs and building a culture that enables staff to respect people’s individual choices and preferences are essential factors in promoting a good quality of life for people who live in a residential setting. Services may find it challenging to implement these changes because they will involve a major rethink in their approach to service delivery.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. Raise awareness through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.

2. Identify a lead with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.

3. Carry out a baseline assessment against the recommendations to find out whether there are gaps in current service provision.

4. Think about what data you need to measure improvement and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.

5. Develop an action plan, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.

6. For very big changes include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.

7. Implement the action plan with oversight from the lead and the project group. Big projects may also need project management support.

8. Review and monitor how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

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6 Related NICE guidance

To find out what NICE has said on topics related to this guideline, see our web pages on:

Patient experience in adult NHS services (2012) NICE guideline CG138.

Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services (2011) NICE guideline CG136.

Social care for older people with multiple long term conditions (2015) NICE guideline NG22.

Transition between inpatient hospital settings and community or care home settings for adults with social care needs (2015) NICE guideline NG27.

Transition from children's to adults' services (2016) NICE guideline NG43.

Quality standard for service user experience in adult mental health (2011) NICE quality standard QS14.

7 Contributors and declarations of interests

Members of the Committee and other contributors to the guideline declared any relevant interests. [Add guideline number to hyperlink] in line with the conflicts of interest policy.

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Declarations of interests

The following members of the Guideline Development Group made declarations of interest. All other members of the Group stated that they had no interests to declare.

Committee member	Interest declared	Type of interest	Decision taken
Gerry Bennison	21/12/2015: Research Advisor for QORU (Quality and Outcomes for Person Centred Care Policy Research Unit) relating to the PSSRU at the University of Kent. QORU undertakes research into Social Care with various work such as Dementia Care, Personal Budgets. The role is remunerated up to twice a year.	Personal financial, specific	Declare and participate.

Mary Gardner	21/12/2015: I work for the British Red Cross who provide low level social care support. My role involves me providing advice and support on good practice and providing quality assurance.	Personal financial, specific	Considered at each meeting. Declare and participate.
Ju Gosling	24/05/2017: I am a trustee of the charity Regard, which is unfunded, and in that role attend various SCIE meetings. Bristol Regard LGBTQI study included in review at GC10.	Personal non-financial, specific	Considered at GC 10 meeting. Declare & participate.
Ju Gosling	24/05/2017: Member of SCIE Co-production network. Paid a user involvement fee for attending meetings.	Personal financial, specific	Declare and participate.
Ju Gosling	12/06/2017 Artistic director of Together! 2012 CIC and Folk in Motion CIC; these are arts organisations and don't include a social care element. None of the funding from any of those activities comes from adult social care funding.	Personal non-financial, non-specific	No action needed.
Paul Jays	08/12/2016: Independent consultant across Social Care and Health on a fee basis, undertaking work for the UK DH, the Northern Ireland Health and	Personal financial, specific	To be considered at each meeting. Declare and participate.

	Social Care Commissioning Board, English Local Authorities and currently the Falklands Island Government. I work through my own Limited Company and I am the sole Director.		
Paul Jays	Chair of a Welsh arts charity for people with disabilities, for which there is no remuneration.	Personal non-financial, non-specific	No action needed.
Mohammed (Sid) Jeewa	11/12/2015: Lay Visitor for Health and Care Professions Council (HCPC). This role is remunerated.	Personal financial, specific	Declare and participate.
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Mohammed (Sid) Jeewa	24/05/2017: Member of SCIE Co-production network. Paid a user involvement fee for attending meetings.	Personal financial, specific	Declare and participate.
Jonathan Kilworth	17/10/2017 Part-time secondment to NHS digital, advising on surveys.	Non-personal financial, specific	Considered at GC11 meeting. Declare and participate.
Alice Maynard	08/05/2016: Trustee/ Director and Chair of Swanswell	Personal financial, specific	Kept under review at each meeting.

	Charitable Trust, a drug and alcohol recovery charity. January 2017: Role no longer active		Declare and participate.
Alice Maynard	08/05/16: Chair of a strategic advisory panel for Dimensions, an organisation that provides social care. This is not a remunerated position.	Personal non-financial, specific	Declare and participate.
Walkiria Moura	14/06/2017 Husband is Chairman of the following biotechnology companies: Canbex Ltd, Intract Ltd, Biomoti Ltd, Oppilotech Ltd These are all research companies and have little overlap with the work of the Committee.	Personal financial, non-specific	No action needed
Walkiria Moura	14/06/2017 Husband is a board member of Sky Medical Ltd, which sells a device for DVT prevention, oedema reduction and wound healing. Some of these products are used by the NHS.	Personal financial, non-specific	No action needed
Matthew Parris	03/02/2016: Employment with the charity Help & Care and Healthwatch Surrey C.I.C., who provide information, advice & advocacy services.	Personal financial, specific	Declare and participate.

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Alec Porter	Jan 2015: NHS England grant to pilot the Accessible Information Standard - £17k, paid to Bradford Metropolitan District Council. I did not make any personal financial gain.	Non-personal financial, specific	Declare and participate.
Alec Porter	Feb 2016: NHS England grant to develop tools to support Accessible Information Standard - £13k. The grant was paid to Bradford Metropolitan District Council I did not make any personal financial gain.	Non-personal financial, specific	Declare and participate.
Alec Porter	12/06/2017: Is in the process of setting up own company,	Personal financial, specific	Declare and participate.

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Tony Prosser	24/05/2017: Member of SCIE Co-production network. Paid a user involvement fee for attending meetings, although to date I have only attended the SCIE Co-production conference and it was unpaid.	Personal financial, specific	Declare and participate.
Jonathan Rackham	16/02/2017: Expert by experience with Care Quality Commission. This role is remunerated.	Personal financial, specific	Declare and participate.
Sophie Staniszewska	01/12/2015 Ongoing review of academic interests.	Personal non-financial, specific	Considered at each meeting. Declare and participate.

Sophie Staniszewska	17/10/2017 Has been approached to join the NICE Implementation Strategy Board.	Personal non-financial, non-specific	No action needed.
Martha Wiseman	21/12/2015: Trustee of Carers UK, elected for term 2013-2017	Personal non-financial, specific	Declare and participate.
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8 Glossary and abbreviations

Glossary

Construct validity

Construct validity can be regarded as an overarching term to assess the validity of the measurement procedure, such as a questionnaire, used to measure a given construct (for example, depression).

Cronbach's alpha

Cronbach’s alpha is a way to measure reliability of a psychometric instrument. 'Reliability' is how well a test consistently measures what it is supposed to measure.

Grounded theory

Grounded theory is a systematic research methodology in the social sciences which involves the construction of theory through the analysis of data.

Internal reliability

Internal reliability assesses the consistency of results across items within a test.

Interpretative framework approach

A research approach that aims to develop in-depth understanding about a topic or subject through observation or interaction.

Purposive sample

Purposive sampling is a strategy where a study sample is purposefully chosen to cover a range of specific characteristics (as opposed to a random sample).

Social care-related quality of life

Social care-related quality of life (SCRQoL) refers to those aspects of people's quality of life that are relevant to, and the focus of, social care interventions.

Test-retest reliability

This is used to assess the consistency of a test or measure from one time to another. Having good test re-test reliability signifies the internal validity of that measure.

Please see the NICE glossary for an explanation of terms not described above.

Abbreviations

Abbreviation	Term
ACP	Advanced care planning
ADL	Activities of daily living
ASCOT	Adult Social Care Outcomes Toolkit
ASCOT-ER	ASCOT Easy Read (questionnaire)
ASCS	Adult Social Care Survey
BCODP	British Council of Disabled People
CEPF	Central England People First
COPD	Chronic Obstructive Pulmonary Disease
CQC	Care Quality Commission
CIL	Centre for Independent Living
DP	Direct Payments
DPA	Deferred Payment Agreement
EOLC	End of Life Care
FHN framework	Fundamental Human Needs framework
HEED	Health Economic Evaluations Database
ICT	Information and communication technology
IMCA	Independent Mental Capacity Advocate
IPP	Individual Programme Plan
LGBTQI	Lesbian, Gay, Bisexual, Transgender, Queer and Intersex

NCIL	National Centre for Independent Living
NHS EED	National Health Service Economic Evaluation Database
NVQ	National Vocational Qualification
OT	Occupational therapist
PA	Personal Assistant
PREM	Patient Reported Experience Measure
QOL	Quality of Life
SPSS	Statistical Package for the Social Sciences
TLAP	Think Local Act Personal

About this guideline

What does this guideline cover?

The Department of Health (DH) asked the National Institute for Health and Care Excellence (NICE) to produce this guideline on the experience of people who use adult social care services (see the scope).

The recommendations are based on the best available evidence. They were developed by the Guideline Committee – for membership see section 7.

For information on how NICE social care guidelines are developed, see Developing NICE guidelines: the manual

Other information

We have developed a pathway and information for the public and tools to help organisations put this guideline into practice. They are available on our website.

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